HOSPICE NURSES IN UTAH: A QUALITATIVE STUDY OF THEIR VIEWS ON HOSPICE NURSING PHILOSOPHY AND PRACTICE

by

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ABSTRACT

The concept of modern hospice care was conceived by Dame Cicely Saunders, a British nurse who later trained as a social worker and doctor. Her mandate was to offer holistic care consisting of physical, emotional, spiritual and psychological support to dying people enabling them to live fully to the end of life. Hospice care has developed differently in the UK and the USA. This qualitative study, undertaken by a British nurse who has worked in end of life care in both countries, set out to discover how hospice care was perceived and delivered by seven hospice nurses in Utah. Emergent themes were consistent with early ideas of hospice care, and included supportive and comfort care that was directed by the patient and their family; unlike acute care, hospice care was accepting of death. Nurses felt that dealing constantly with dying was hard, but not necessarily stressful; they discussed coping mechanisms. The merits of the interdisciplinary team were praised as both a support to the family and the nurses. The reasons underpinning the routine taking of vital signs was investigated, with the conclusion being that it is done mainly to meet the perceived needs of the family of the patient. Documentation was seen as unwanted necessity, performed mainly for legal reasons. All nurses reported that hospice nursing was extremely rewarding, despite the inherent repeated loss and grief.

"The nurse in her skilled competence and compassion, has a unique place to give each person the essential message, 'You matter because you are you and you matter until the last moment of your life. We will do all we can to help you, not only to die peacefully, but to live until you die."

Dame Cicely Saunders, as quoted in Ferrell, B., and Coyle N. (2001) Textbook of Palliative Nursing New York, NY: Oxford University Press, (p. v).

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MODERN HOSPICE CARE IN THE USA AND THE UK

Dame Cicely Saunders (1918-2005), a British nurse who later trained as a social worker and a doctor, is generally credited with being the inventor of the modern hospice movement. A few hospices were in existence before her advent onto the health care stage, and it was whilst working in one of these, St. Joseph's Hospice in London, that she befriended David Tasma, a young Jewish patient who inspired her work. A survivor of the Warsaw Ghetto, David Tasma's plea to Saunders, of wanting "what was in her mind and in her heart," was to become a guiding theme for care of the dying, a combination of emotion and intellect (Clark, 2006, p.xiv). David Tasma's second request to "be a window in her home" was realized in 1967, when St. Christopher's, the first modern purpose built hospice was opened in London. Saunders felt strongly that the dying need the community and indeed that the community also needs the dying to compel it to think of eternal issues, to listen and to give to others. Furthermore, she branded societies that shun the dying as having an "incomplete philosophy" (Saunders, 1961, in Clarke 2006, p.39). Although she felt that the ideal death was dying in one's own home, she stated in 1961 that there was a great need for "homes that specialize in this most rewarding field of medical and nursing care" (Saunders, 1961 in Clark, 2006, p.39). These homes were to have a spiritual basis to "sustain the staff and the life of the whole place" (Saunders, 1961, in Clark, 2006, p. 39)." St. Christopher's was built

on a Christian and medical foundation (Clark, 2006) but embraced people of all faiths.

Saunders acknowledged the early religious foundation of medieval hospices which were resting places for weary travelers, as inspiration. She describes the modern hospice:

> The medieval hospice spoke of "Our Lord's the Sick." The modern hospice is people meeting people with openness as well as skill, and using both in looking at the many reasons for the pain that brings patients and families for help. So pain, a whole experience, is seen not only as physical but also in its emotional and social and spiritual aspects, the suffering of a whole person. (Saunders, 1989, in Clark, 2006, p.226)

This multifaceted approach to care of the dying has been adopted by the World Health Organization (WHO) which defines palliative care as,

> An approach that improves the quality of life of patients and their families facing the problems associated with life threatening illness, through the prevention and the relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. (WHO, 2002, p.83)

Following Saunders' first publications on care of the dying, she made a tour of the United States, visiting medical centers and universities and lecturing on this subject. According to Buck (2007), her descriptions of hospice philosophy resonated with a few nurses, clergy and physicians who had become discontented with the way medical care for the dying had become increasingly impersonal and technologically managed. Buck reports that Saunders' lectures acted as a catalyst to ignite the American hospice movement.

One prominent American nurse whom Saunders met was Florence Wald who was to become a lifelong friend. Wald, Dean of the School of Nursing at Yale, has been referred to not only as the mother of hospice nursing in the United States

(Lentz, 2004) but as the mother of American nursing (Buck, 2007). Wald was a leading reformer of nursing education, advocating that nurses rid themselves of administrative duties and return to the bedside. Using St. Christopher's as a model, yet wanting hospice to have an "American Flair" (Buck, 2007, p.128), Wald and her colleagues eventually opened a hospice in Connecticut. By 1978, Hospice Inc. had been formed and provided advice to a hundred or more fledgling hospice groups formed by idealistic nurses, clergy and physicians around the country (Buck, 2007).

Saunders also credits Elisabeth Kubler- Ross who interviewed patients in a large general hospital in Chicago during the 1960s about dying, for preparing the groundwork for the growth of Hospice homecare teams in the US (Saunders, 1998). Dr. Kubler- Ross emigrated from Switzerland to the United States working in hospitals in Chicago, Colorado and New York and was appalled by the standard treatment of dying patients. Determined to "breakthrough the layer of professional denial that prohibited patients from airing their innermost fears and concerns" (Elisabeth Kubler- Ross Foundation, 2011, para.4), she would sit with patients, allowing them to express their feelings as well as taking them to lectures with her. Her sister states that, "she was always very proud that her work helped bring the hospice movement into the mainstream in the US" (Elisabeth Kubler- Ross foundation, 2011, para.5).

Developments of the hospice movement during the 1960s can also be viewed as a backlash to the "medicalization of dying" (Illich, 1995, as cited in Mercer & Feeney, 2009). With advancing technology, many previously fatal illnesses became curable, leading to an expectation that death was a thing that could

be delayed or even avoided. To some extent this is still a barrier to accepting hospice care. Remington and Wakim (2010) noted that attitudes towards hospice are similar in both the UK and the US with the transition of curative to palliative care sometimes viewed negatively as "giving up" and avoided (p.19).

According to the National Hospice and Palliative Care Organization (NHPCO, 2011), the percentage of hospice deaths in 2008, had risen to 38.5% of all deaths in the USA. Studies of over 235,000 Medicare patients over age 65 examined between 2003 and 2007, however also showed that 29% of patients with advanced cancer still die in hospitals and intensive care units and 6% of these still received chemotherapy in the last 2 weeks of life (Dartmouth Atlas of Health Care, 2010, para. 2). Shannon Brownlea in her book *Over treated* (2007) describes this phenomenon:

> Our relentless search for wellness through medicine has created a kind of therapeutic imperative, the urge to treat every complaint, every deviation from the norm, as a medical condition. We've come to believe that if it can be performed, it should be performed; if a treatment can be used to lengthen life even incrementally, it should be used, regardless of whether the intervention will improve the individual's sense of wellbeing, or is what the patient really wants. Families often tell doctors to "do everything possible" for their elderly and dying loved ones, often without realizing that "doing everything" won't necessarily stave off death for long, but could make the patient's last few days or weeks more miserable than they might have been....this happens not because doctors or families wish them harm, but because everyone is stuck in a system where all the forces point in the same direction toward more medicine rather than toward more compassionate care. (p.206)

Ellershaw (2003) cites this focus on cure, with its continuation of invasive procedures, investigations, and treatment which occur at the expense of the patient's comfort, as also responsible for creating a barrier to doctors diagnosing a dying process.

Johns (2004) describes hospice care in today's world,

> Hospice care is founded on the core tenet that patients should be helped to live until they die and that dying is a natural part of living despite the general taboo of dying within society (Twycross, 1986). Hospices have a strong ideal of the 'good death'; a death in which the patient drifts off peacefully, with dignity at the right time, in comfort with symptoms well controlled, with their right to self determination respected as far as possible, with open communication and acceptance by the whole family, without encroachment of unnecessary medical intervention. (pp. 13-14)

The idea that good deaths are in hospice and bad deaths hospital is however seen by Walsh (2002) as worth discussing. She cites Ackerman who feels that not everybody might choose hospice and 'to go gently into the night.' Walsh concludes that where we die may not matter as much as how we die; good palliative care should be able to be practiced across settings.

Saunders' idea of helping a person 'live until they die' is a sentiment shared by many others, and espoused by some as a time for growth and finding meaning (Byock, 1997; Kuhl, 2002). Recognizing the personhood of a patient is seen within hospice philosophy as most important to the dying patient. Hutchings (2002) states that quality of life is dependent on the meaning and personal context as defined by the patient and not the health care professional. Cassell (1991) believes that suffering can ensue if a person feels that the very sense of who they are is in jeopardy. Byock (1997) also says, "For many people there is no worse pain, no greater suffering than when they feel they have lost their dignity" (p.85). Chochinov (2005) has used his research in this area to develop "dignity therapy" for people at the end of life.

As well as helping the individual during the dying phase, hospice philosophy recognizes the need for support of the family. Kubler Ross (1969) states that "the

family usually needs more help, understanding and support than the person himself" (p.124). Ferrell and Coyle (2008) discuss "shared suffering" and point out that little attention has been paid to the collective suffering of family care givers, but there is evidence that there is reciprocal suffering and pain as the physical and emotional burdens of the patient are taken on by them. Ferrell and Coyle also point to the nurse as the one who can move a family care giver from a sense of helplessness to a sense of helpfulness.

Despite shared beginnings, and the exchange of knowledge in the early days of the hospice movement, hospice care has developed differently on either side of the Atlantic. Dame Saunders recognized that North America was the first place where patterns of care other than free standing hospices were developed. This suggested to Saunders that provision of hospice care did not have to be limited to a separate building, but hospice attitudes and skills could be practiced across a variety of settings (Saunders, 1998). Hospice in the USA has been described as both "a well coordinated set of services intended to relieve or ease the varied symptoms or side effects of a terminal illness" as well as "the concept or philosophy of care practiced by these specialized programs" (Beresford, 1993, p.8).

Hospice care is one of the fastest growing segments of the health care industry in the US. According to Marelli (1999) there is general dissatisfaction with end of life care and people are searching for alternative ways and treatments, changing their belief systems relating to death and illness. Another reason Marelli suggests for the popularity of hospice for some is the renewal of the view that

spirituality is an important part of life and illness, and patients and families having a desire to make their limited time life affirming and valuable.

According to Doyle (1998) cost containment and financial viability have been stronger pressures on the models of care in the US than in the UK and account for home hospice care becoming the more prevalent model in the US. The US Congress created legislation establishing Medicare coverage for hospice care with the Medicare hospice benefit being made permanent in 1986. Most states also provide Medicaid coverage for hospice services, as do most private insurance companies, benchmarking their hospice coverage to the Medicare standard. The Medicare Hospice Benefit includes the following services: nursing care available 24 hours a day, medical social work, physician services, counseling, home health aides, physical therapy, occupational therapy and speech and language therapy, medical supplies and equipment, all medications used to relieve the symptoms of terminal illness, short term inpatient care for symptom management, respite care for families and continuous nursing care in the home during periods of medical crisis. These benefits are funded as a capitated per diem fee paid to the hospice agency. The Medicare hospice benefit and the accompanying licensure regulations restrict hospice care by stipulating time frame eligibility for services; specifically the recipient must have been given a prognosis of less than 6 months life expectancy. Furthermore, hospice patients must agree to forgo curative treatment to be eligible for hospice coverage.

That the hospice philosophy, its skills and attitudes, could be practiced in a variety of settings, led to adaptation of hospice care to the home environment in the

USA and Canada, long before Britain incorporated hospice care in the home. In contrast, purpose built hospice buildings are more widespread in the UK, and community services are often run from these buildings. For patients wishing to die at home British policy seems to favor encouraging generalist rather than specialist physicians and homecare teams, encouraging them to include palliative care in their repertoire of services. Medical management of the dying person falls to the patient's general practitioner (GP).

Community nurses case-manage, deliver nursing care and organize other services on behalf of patients and their families. Often known as district nurses, community nurses are the nearest equivalent to both home hospice nurses and homecare nurses in the US. They deliver palliative care as well as meeting the needs of the generalist patients on their caseloads. With emphasis on primary care rather than secondary (hospital), care in the UK, there are increasing demands on these nurses. Cook (2006) cited by Burt et al. (2008) lists these possible roles as expert clinicians, case managers, business entrepreneurs, social entrepreneurs, data collectors, service commissioners, service providers, hybrid health and social care workers, public health workers, and workforce developers. Community nurses are RNs, the team leader is expected to have a specialist qualification in community nursing, and some community nurses also possess a bachelor's level hospice qualification.

The multidisciplinary team equivalent is made up of the GP who, as suggested under the MacMillan Gold Standard Framework (a set of government recommended guidelines to improve palliative care) meets monthly with the

community nurses attached to their office as well as assigned specialist palliative care nurses from a hospice organization.

The term "hospice nurse" in the UK is reserved for the specialist palliative care nurse, usually an RN with the additional community nursing degree. These hospice nurses do not see all the patients who die at home, only a small proportion of them with specialist needs (NCHSPCS 1995 in Evans & Walsh, 2002) usually those deemed as having emotional problems or uncontrollable symptoms (Skilbeck et al., 2002). Funded in part by the MacMillan foundation these are often known as "MacMillan Nurses." These nurses work in an advisory capacity both to patients directly as well as giving advice and sometimes practical help to nurses and GPs. A generalist social worker could be called upon to help as needed, and there may also be one or more social workers attached to the hospice, but there is generally no chaplain availability for patients in their own homes.

Various advantages emerge from this arrangement: The patients continue to be cared for by their own family physicians and home care nurses with whom they may be familiar if they have long standing illnesses. Disadvantages identified by Burt et al. (2008) to having community nurses deliver most of the palliative care to patients at home are the stresses associated for these nurses switching from palliative care to other aspects of their caseload, the unpredictability and time consuming nature of palliative care and having to juggle case management and other responsibilities around this. Nurses in Burt's 2008 focus group study felt that the palliative care part of their job was not acknowledged by their managers and their needs went unsupported. These nurses could see the importance of palliative care,

were committed to its delivery and recognized its rewarding nature, but found it a challenge.

The funding for end of life care in the UK comes from two sources. Community nurses, GPs, and social workers are funded through the National Health Service (NHS). Specialist Palliative Care Nurses, hospice buildings and other specialist services are funded mainly by charitable donations such as the Macmillan Cancer Fund, and local fundraising. As an illustration, the proportion of funding from one local UK hospice in 2010 was as follows, voluntary fundraising, 52%; Primary care trust, (National Health Service) grant, 28%; local lottery and hospice shops, (mainly selling second hand clothing, books etc.) 13%; educational income, (university level courses for health care professionals provided through the hospice) 4%; and investment income, 3% (Hospiscare, 2010, p.8).

Another charitable organization playing a large part in the provision of palliative care in the UK is the Marie Curie Memorial Foundation. Independently active before the emergence of the hospice movement, the foundation was responsible for highlighting the suffering of cancer patients, funding research, and currently provides nurses that can be called on to supplement the care given by the community nurses. This service is particularly valuable for providing a nurse to sit with the homebound patient at night to provide respite for families. Cicely Saunders recognized this particular service as very supportive (1995, in Clarke, 2006).

Produced by the Marie Curie Palliative Care Institute in Liverpool, the Liverpool Care Pathway (LCP) is a document used by nursing staff caring for patients in the last few weeks or days of life to ensure quality and equitable

palliative care in all settings. This document is designed to accompany the patient to a new location of care. It documents usual symptoms and measures to control them in a check list format, and includes a narrative page to document deviation from proposed best practice. The LCP was produced to ensure that all dying patients, their relatives and care givers receive a high standard of care in the last hours and days of life (The Marie Curie Palliative Care Institute, 2010). This document has been adapted for use in Australasia and other Westernized Countries. Use of the LCP in Western Australia was reported to have improved discussion and documentation of end of life issues, involvement of families, and generated improvements in assessment of individual and family's religious and spiritual needs. Management of dyspnea was also improved. Discontinuation of inappropriate medication, and other interventions including anti-biotic and intravenous, and defibrillation were noted.

When making comparisons between the UK and the USA it is important to note that there are also regional differences in both countries. In the UK unequal spending and allocation of services from region to region is known as a "post code lottery" of care. Although there is a 'national' health service, geographical regions have discretionary powers regarding health care spending. This lottery of care is felt by some to extend to hospice services (EADT News 2011). With respect to the US, Byock (1998) views the provision of Hospice care across America as uneven, and its quality inconsistent. In the US Medicare data analyzing Health Care use in America (Dartmouth Atlas 2010) found striking differences in whether patients died while receiving hospice care or not, and this appeared to be dependent on where

they lived and received care. According to the Dartmouth Atlas statistics Utahns at the end of their lives are less likely to die in hospitals than other Americans, and receive more days of hospice care than in any other state but one. Utah's figures for hospital deaths are lower than the national average ranging from 7-22.6%, its residents spending the fewest number of days in hospital at the end of life: 6.4 days compared to a national average of 11.2 days (Dartmouth Atlas cited by Henetz, 2011, para.1).

Systems of hospice care in the UK and the USA have been compared according to structure and funding by Remington and Wakim (2010). Their article reviewed the similarities and differences between hospice care provision in the USA and the UK and concluded that barriers to accessing hospice care in the US included restrictive Medicare eligibility criteria, financial difficulties and location of care, as well as the requirement for a designated family caregiver. In addition, Medicare does not pay for hospice services and room and board in an inpatient facility, creating a financial burden for the patient or family. In the UK, there are few financial barriers; all care is provided free at the point of delivery. Whilst a referral for hospice by a physician is required, the time frame for referral is more generous than the 6 months before expected death that Medicare prescribes in the US, being roughly a year.

LITERATURE REVIEW

A search was made of the electronic databases CINAHL, Medline, and PsycLIT using the terms hospice and nurs*. Only research studies published from 2001-2011 were included. This pool of 436 articles was further refined to include only studies that explored the qualities of hospice nurses, the stresses that they face, their coping strategies and their resilience, or the skills required of nurses to practice in the hospice setting. Fourteen studies were retained: 6 British, 6 American, 1 Canadian and 1 Dutch study.

Qualities of Hospice Nurses

According to Gaydos (2004), hospice nurses are regarded by the general public and other nurses as being "special." One explanation Gaydos offers for this perception is the willingness of hospice nurses to provide care when there is no hope of recovery, suggesting that most nurses prefer to work in settings where there is at least a possibility of a healthy outcome. Gaydos used co-creative aesthetic inquiry to look at the life journeys of hospice nurses, what brought them to hospice work, the life experiences that have equipped them for this role and the transformations they have realized through hospice work. Interesting narratives were derived from the lives of these hospice nurses and common themes emerged: the qualities of resilience and endurance built through previous life experiences, the sense of

hospice nursing being a calling more than a job, and the part that spirituality played in the hospice nursing role. This article illustrates how for hospice nurses their work can be far more than a job. Life experiences have shaped the care they give, and nursing the dying can give them a different perspective on life, in turn changing them.

In a UK study, Jones (2003) also examines this 'specialness'. He describes the daily work environment of hospice nurses as filled with patients and health professionals emitting and containing strong feelings, including aggression, rage, despair, hope, hopelessness and feeling special. In this qualitative study, Jones draws from conversations of hospice nurses in a clinical supervision group setting. Jones selected the experience of one nurse from this group to illustrate projective identification, that is, how strong relationships between a hospice nurse and patient can be helpful, but he also pointed out the drawbacks of the intense close relationships that are part of being special warning that these are likely to lead to burnout.

Evans and Hallett in their study (2007) describe the hospice nurse drawing upon ways of knowing that have been learned over a period of time. Giving comfort care requires a synthesis of knowledge, experience, intuition and an existential understanding of how to enter a patient's world and be with the vulnerable patient. Evans and Hallett espouse that comfort care is only achieved through wisdom, which includes experience and empirical knowledge, coupled with humanistic intent, which could be seen as echoing Saunders' philosophy that a combination of emotion and intellect is needed to work with the dying.

Johnston and Smith (2006) performed what they described as a unique study in the UK, as it interviewed both hospice nurses and their patients. Overall they found that important characteristics of expert palliative nurses included interpersonal skills, a willingness to listen, being someone the patient feels able to talk to, an interest in knowing patients as people, and an ability to recognize that some patients may need to feel in control even when it would appear that their state of health does not allow for this (Johnston & Smith, 2006). I found this study interesting in that "the heart" seems to triumph over "the mind" in importance to these patients. Technical skills figured in things the nurses felt were important, but not in the patient's estimation. Both nurses and patients agreed that the most important traits for a hospice nurse to possess were interpersonal skills and qualities such as kindness, compassion and genuineness. The authors called for more research to observe whether nurses actually do practice in the way they and the patients say they should.

Stress in Hospice Nursing

A common focus for many of the studies I found concerning the work of hospice nurses was stress and burnout, often including how hospice nurses cope with this. Abendroth (2006), in an attempt to predict the risk of compassion fatigue in hospice nurses, describes burnout as physical, emotional, and mental exhaustion caused by long term exposure to emotionally demanding situations and considered it a precursor or risk factor for compassion fatigue. Compassion fatigue as defined by Figley (1995, cited by Abendroth, 2006) is "a secondary traumatic stress reaction

resulting from helping or desiring to help a person suffering from traumatic events" (p. 347). Abendroth's study shows that hospice nurses are at moderate to high risk for compassion fatigue, experiencing an average of seven patient deaths a month, and having to communicate compassionately and professionally with distraught families, before during and after the dying process. Those at highest risk were those who put their patient's needs before their own, reflecting what she saw as an unhealthy level of empathy. This study presents the potential adverse effects of caring for the dying.

Martens (2009) carried out a quantitative study examining stress factors in both home and inpatient hospice nurses. This American study surveyed nurses from 14 midwestern hospices. The top stressors identified by participants were making a mistake when treating a patient, insufficient personnel, fellow workers not doing their jobs, inadequate managerial support, disagreement with a medical professional regarding the treatment of a patient, and personal insults from patients or families. The least stressful aspects of their work were caring for the emotional and spiritual needs of the patients and families, and communicating with a patient and family about death. This study suggested that the parts of the job that would be seen by the general public or other nurses and health professionals to be stressful such as confronting death, and dealing with loss were not stressful, instead not being able to perform their job as they would like because of excessive demands, and a perceived lack of support were identified. This study showed that although many aspects of the job are seen as potentially stressful, hospice nurses seem to be able to deal with them.

Kulbe's 2001 study also identified three more potential stressors, namely, paperwork, working with physicians who do not understand hospice philosophy, and too many patients dying as potential sources of stress. After finding so many studies on this aspect of hospice nursing, I was interested to find out how the nurses I would be interviewing experienced stress, and how they managed it.

Hospice Nurse Skills

I found several studies that explore the practice of hospice nurses. Evans and Hallett (2007) as well as examining the meaning and practice of "comfort care" looked at how this is pursued, and provided. In defining this care, nurses identified pain control, with an assumed knowledge of appropriate analgesia, as well as emotional and spiritual issues. A US ethnographic study by Wright (2001) investigated the skills experienced hospice nurses perceived as essential to their practice, and identified 11 categories. Four of these categories addressed skills: assessment skills, communication skills, management and technical skills. The other seven dealt primarily with knowledge: end stage disease knowledge, signs of impending death, palliative therapeutics, collaboration between disciplines, advocacy, philosophy and ethics of hospice care, and family dynamics. Within the theme of assessment, the importance of technical skills of the hospice nurse was highlighted, suggesting that hospice nurses need to be able to use kangaroo pumps (for tube feeding), suction machines, IV pumps, ventilators and other equipment. This study seemed to confirm the idea that technology seems to be regarded as an important part of hospice care in the USA.

BACKGROUND TO THE STUDY

As a community nurse who has worked with dying patients in England, I recently started working for a home hospice agency in Utah. The differences in practices between the UK and the US intrigued me. Although the service populations are similar, and the basic goals and values of the organization and the staff were essentially the same, clinical practices appeared to differ. Preparation for the National Council Licensure Examination State Board Examinations, as well as other examinations requisite for practicing in the USA, convinced me that nursing in the USA is more technical than in the UK. I was surprised however to find that this more technical approach also extended to end of life care. In my observation, this was illustrated in the routine taking of vital signs and oxygen saturation levels (SATs), as well as in the frequent provision of oxygen and the occasional use of intravenous (IV) therapy. I had been prepared for the expectation of extra documentation. Even Cicely Saunders, on her trip to the USA in the 1960s, talked with a British nurse who told her that the administration and paperwork in the US were more extensive than in England (Buck 2007).

Gunhardsson et al. (2008) examined documentation in a palliative care setting; they reported that documentation in palliative care is an important task for nurses, for the communication between themselves and different professionals in the team. They state that it is also necessary to judge the standard of care provided, and

facilitates provision of continuous and individualized care by the nurses. What I observed was that the documentation served another purpose beyond detailing the patient's condition; much of it was oriented towards billing and fulfilling Medicare and insurance eligibility requirements. This seemed to be peculiar to the Healthcare system in the US. Kulbe (2001) observes that each year the paperwork requirements from Medicare and insurance companies continue to grow.

Documentation of nurse visits to end of life patients in the particular Utah hospice agency that I am employed by are documented in two formats. The nurse visit form requires documentation of vital signs, weight including recent loss, pain control, and full assessment of all bodily systems. In addition, family adaptation, equipment and medication use, as well as spiritual needs and documentation with family are noted. There is provision on the form for narrative. The nurse visit form is used once a week; documentation of other visits is in the form of a narrative. All nurse documentation is kept at the agency office.

In the UK, when it is recognized that a patient is at the end of life the Liverpool Care Pathway forms replace the usual nursing documentation, and like other patient records these are kept in the house. These forms set out goals of comfort to be realized in all usual physical areas of symptom management at end of life for example, pain, dyspnea, nausea and restlessness, as well spiritual care, family and physician awareness of the patient's condition etc. and a narrative section where it is expected that the nurse will record any variance to the basic need of a dying person. There is no place on these forms to record vital signs.

Another phenomenon I observed was the interdisciplinary working of the team—it was more extensive than I imagined, and although I had been accustomed to interdisciplinary team meetings for patients suffering from chronic disease and at risk for hospitalization, I had not been exposed to extensive interdisciplinary teamwork in care of the dying.

I was particularly interested in the routine recording of vital signs. When I questioned staff on their reasons for taking vital signs, the answers I was given were as varied as the people I asked. One nurse explained that it is a part of 'Westernized Medicine' [*sic*] and then stated that it was the doctors who needed this information, this was confirmed by one of the doctors. Another nurse said she thought it was more for the nurse's benefit than the patient's. It appeared to me that many nurses seemed to feel it was just "what we do as nurses." One older nurse felt that her lack of zeal in taking vital signs was being "part of the old school which was not as technical (as the younger nurses)." One answer indicated that the information from vital signs helped determine the patient's prognosis, or closeness to death. A leaflet routinely given to patients, and their families, "Signs and Symptoms of Approaching Death" (Rocky Mountain Hospice, no date), seemed to endorse the value of knowing vital signs; as the leaflet describes as one sign of imminent death, "blood pressure dropping dramatically from patient's normal blood pressure range, (more than a 20 or 30 point drop)" and "systolic blood pressure below 70, diastolic blood pressure below 50" (p.2), which suggests that this was being monitored by nurses for the purpose of prognosticating. My personal observations supported the importance that some families placed on having these measurements.

Examining the US literature on the subject of taking vital signs at the end of life revealed little convincing evidence of the necessity of vital sign measurement, particularly at the very end of life. The European Association for Palliative Care in a literature review of this subject acknowledged that pulse and respiratory rate have occasionally proved significant in the prediction of cancer survival times, but primarily in the earlier stages of the disease (Maltoni et al., 2005). A British study does, however, list abnormal vital signs with other predictors such as weight loss, nutritional status, abnormal laboratory values, the presence of co-morbidities, and increased dependency in ADLs (activities of daily living), citing vital signs as useful tools to identify older people who might have a prognosis of 6 months or less and might benefit from palliative care services (Coventry et al., 2005).

As far as the routine taking of vital signs in patients at end of life Kehl (2008) states, "vital signs need not be taken routinely, unless family request" (p.410). Furst and Doyle (2005) agree stating that blood pressure need not be taken, as it adds nothing to the care plan. Berry and Griffie, in Ferrell and Coyle (2010), state that when death is approaching, nurses need to examine the rationale for measuring vital signs. They propose that unless treatment is going to change on the basis of blood pressure and pulse readings, measurement should be stopped, respirations can be visually noted, maintaining that measuring the temperature should be continued otherwise, "the time spent taking vital signs can be channeled to assessing patient comfort and the provision of family support" (pp. 631 & 633).

Sandelowski (1999) observed the relationship between nursing and technology, "Nurses have always used a variety of tools instruments and machines,

including thermometers, and cardiac monitors…. to appraise, treat and comfort patients" (p. 198). She cites early 20th century attempts to use technology and nurses combined to advertize American Hospitals (Sandelowski, 1999). Disturbing a terminally ill patient may also not be as bad as nurses think. Meystre and Burley's 1997 study questioned people in the advanced stages of cancer about the acceptability of certain investigations and procedures, and found that patients gave measurement of temperature and blood pressure 10 out of 10 on the acceptability rating scale, whereas nurses scored them at a 7.

Johns (2005) worries however that technical tasks might have more precedence or urgency than caring behavior. He cites Musk (2004) who suggests that the nurse may even use technology as a barrier against developing relationships that may become emotionally draining. Johns also wonders whether "machines dominate the 'clinical gaze' and obscure the person or that "The person is seen primarily in the way the machine interprets him" (Johns, 2005, p. 151) and goes on to suggest that the nurse could miss sensing and understanding other aspects of a patient's suffering, such as "soul pain." Ferrell and Coyle (2008) illustrate the point that there may be more important issues as a patient nears death. In the opening paragraphs of their book "*The nature of suffering and the goals of nursing*," the authors paint a picture wherein a nurse forgoes taking vital signs to make the patient and her mother a cup of tea; the last they might take together (pp. 3-5).

STUDY DESIGN

The purpose of this study was to explore beliefs and practices of hospice nurses in Utah and to determine what philosophies and systems underpin their practices and the care they provide. I sought to discover their views regarding the taking of vital signs, documentation and the merits of interdisciplinary practice. As a nurse who had worked in end of life care in the UK, I was particularly interested to look at how American culture may influence hospice philosophy, and whether in some instances it overrides it.

Research Questions

As my personal observations led me to choose the subject of this study, they also helped fashion my three research questions. What is the participant's (hospice nurse's) idea of hospice philosophy? How does the participant see this philosophy articulated in the provision of care? What other factors does the participant feel might influence hospice care delivery, generally or personally?

Qualitative Research

I chose a qualitative research technique for this study, which has often been recognized as more suited to palliative care, as it incorporates subjective experiences which according to Watson et al. (2009) are less easily measured

mathematically. I deemed a phenomenological approach suitable for exploring the lived experiences of these hospice nurses, as well as their interpretations of their behavior. Phenomenological research takes an inductive and interpretive stance based on the work of Heidegger (1962) that allows for a manageable but rich description of actual nursing practice (Benner 1984). This type of inquiry has been used successfully in studies that examine nursing practice (Benner, 1984; Madajar, 1986). As a hospice nurse myself I expected to supplement the interviews with my own observations (Polit & Hungler, 2001).

Padgett (1998) describes the researcher as an instrument, and as such must have amongst other abilities: self-restraint with the discipline to keep a critical distance, flexibility, reflexivity, the ability to examine one's self and a lack of theoretical rigidity. Padgett also evaluates the merits of studying the familiar versus the unfamiliar. By studying a field that is familiar to a researcher, one has the advantages of accumulated knowledge about the topic, and an easier entrée and development of rapport with respondents. As a hospice nurse within the agency, the entrée and to some extent the rapport were already established, as was knowledge of the topic. The disadvantages Padgett notes are being too close to the subject in question, risking familiarity and personal assumptions that might blind one to new perspectives. As a foreign nurse, I felt I was in a unique position, my ability to be an outsider was natural, and the familiar (end of life care in this setting) was to some extent also unfamiliar. The vantage point of an outsider, with the distance needed to uncover implicit cultural roles and norms (the one advantage that Padgett cites for studying the unfamiliar) was also mine. Whilst claiming the advantages of "having

a foot in both camps," the familiar and the unfamiliar, it was necessary to recognize the disadvantages of both. It was important to take Padgett's advice and identify my culture based assumptions as personal biases, and recognize and assure my respondents that I was there to learn from them (Padgett, 1998).

Bracketing is the term used in phenomenological studies for the process of identifying and holding in abeyance any preconceived beliefs and opinions about the study (Polit et al., 2001), Heidegger's predecessor Husserl believed it was necessary to do this in order to expose the true essence of the lived experience (Stumpf, 2008 cited by Mc-Connell Henry et al., 2009). Heidegger however believed this was not possible, that past and present influences always influence present and future dealings (Mc Connell et al., 2009). In explaining the philosophies of research relevant to nursing Mc Connell et al. cite Gadamer (1975) who argued that the history and values that the researcher brings to the environment make the research meaningful to its consumers. Although bracketing may not be entirely possible, Mc Connell et al. recognize the necessity to represent the participant's perspective as accurately as possible. It was important to be aware of my preconceived ideas concerning the nature of hospice care, and hospice nurse practice and attempt to put these aside at both the interviewing stage of the study, taking care not to direct the responses, as well as at the data interpreting stage, not to choose data that supported my own hypotheses. Evans and Hallett (2007) in their hermeneutic phenomenological study of the work of hospice nurses stated that they were obliged to maintain an awareness of their own preunderstandings of the ideas under study, recognizing that these preunderstandings might have a prejudicial

influence on the data, yet perceiving that these ideas could also be used to enrich the process of interpretation.

Method

A semistructured interview guide was formulated to explore the research questions (Appendix B). In the tradition of qualitative research, this approach enables the researcher to direct questions formulated in advance to ask of respondents, but also allows for additional questions to be incorporated on the spot. The respondents' perspectives can be explored in a free-flowing manner, and additional content brought up by respondents can be probed further, particularly when unexpected themes emerge. Thus both the researcher and the respondents guide the study interview.

Sampling

A convenience sample was drawn from the hospice in which the author is currently employed, under the Career Practical Training program of the University of Utah. Purposive sampling was used to select a wide variety of persons in terms of age, gender, qualifications and experience. Table 1 shows the demographic information of the respondents. Few studies have considered the views of male hospice nurses; almost all have concentrated on middle aged women, who appear to make up the largest percentage of hospice nurses (Abendroth, 2006; Gaydos, 2004). Two of the seven hospice nurses I interviewed are males. The majority of studies I found used only nurses with many years of experience in hospice, unless they were

Table 1

Demographic Information of Respondents

	Gender	Age	Qualification	Time in Hospice
Nurse 1	Female	25	BSN	2 Years
Nurse 2	Female	35	RN	1 Year
Nurse 3	Male	31	RN	4 ½ Years
Nurse 4	Female	58	BSN	9 Years
Nurse 5	Female	54	BSN	5 Years
Nurse 6	Female	64	RN	4 ½ Years
Nurse 7	Male	71	BSN	6 Years

specifically looking at the educational needs of newer nurses. In this study I selected 1 nurse with 2 years experience, another with only 1 year of experience to add variety to the sample, and to represent a cross section of practicing hospice nurses, many of whom have not had a long career in hospice. Most of the respondents worked daytime shifts, but I purposely included 1 nurse who covered the out of hours shifts, as I presumed that there might be added challenges to working alone with little support from the interdisciplinary team. In my own work as an on call nurse, I had experienced some of these challenges first hand. To explore a wider variety in the understanding of hospice philosophy, I sought the views of a hospital based specialist palliative care nurse following data collection from the hospice nurses.

Procedure

Approval for the study was obtained from the University of Utah Institutional Review Board. Consent to interview nursing staff was obtained from the Director of Nursing of my employing hospice agency. Informed consent documents were given to participants, with a description of the study and safeguards for privacy and confidentiality explained. All participants approached readily agreed to take part. Interview times ranged from 15 to 55 minutes, and were audio recorded and transcribed verbatim by the author. All respondents were interviewed in private in an office setting; several of these interviews were interrupted by phone calls that had to be taken by the respondents.

Interpretation of the Data

Hallett and Jones' (2007) diagrammatic representation of the interpretive process was followed to facilitate data interpretation (Appendix B). Hallett and Jones describe three stages of data analysis: interpreting individual data with the emergence of first level themes, interpreting collective data, with the emergence of second level and major themes and finally, interpretation of integrated data, and the emergence of the story. This approach is based on the idea of significant statements put forward by Colazzi (1978) and Van Manen (1974) cited in Evans and Hallett (2007) which supports thematic formation as a useful reflective tool in phenomenology (p. 745).

STUDY FINDINGS

Hospice Philosophy

Each interview began with the question, "What is your view of hospice philosophy?" Four of the nurses talked about providing comfort, or "comfort care." Most respondents also mentioned support, or "supportive care," some of them contrasting this to curative medical treatment. Quality of life was paramount, as illustrated by one nurse's expression, "helping to make life as good as it can be, for as long as it can be." Hospice was also seen as an area of nursing where death was not a "taboo" subject. Care for the patient was seen as 'patient led' by being geared to the individual needs of patients, "whatever those needs may be." Success was often measured in terms of whether the patient met their own goals. Getting to know the patient was imperative, as was listening to the patients, and helping them make decisions and form goals that were based on their abilities and desires. A consensus view of interviewed nurses was that holistic care was most important in meeting all aspects of a patient's needs; physical, mental, psychosocial and spiritual. All the nurse respondents recognized that hospice was a service provided for the person with the terminal illness as well as their family, both during and after the patient's death.

Comfort Care

Comfort was mentioned in all the nurse narratives. Nurse 4 started her description of hospice philosophy with, "it's to give comfort to people in the last stages of their life…." Nurse 5 connected comfort with support, as did Nurse 6, "having someone to help them through…" she also equated comfort with ease and peace. Nurse 2 linked comfort to dignity, and Nurse 7 to symptom control, "pain relief and that sort of thing." Comfort was seen as being "as pain free as possible and having as good a quality of life as possible until it's over." Comfort was also perceived as being surrounded by the things and people that had meaning for the patient.

Personalized Care

A common theme was that hospice care is geared to the wants and needs of the patient, more so than in any other type of nursing. It was important for the nurses to find out what was important to the patients, to listen to them, get to know them, find out what could be done to enhance the time they had left, and help them "make decisions for their own lives." The patient should be encouraged to be in control, and say, "I don't want that." The care should be "geared to their needs" and "based upon their abilities and desires." Hospice Nurse 6 compares care for the dying before the hospice program with care now,

> If you wanted care and you couldn't do it at home, then it was just-- send somebody to a facility, and even in the facilities the care wasn't always hospice care, it's just there was somebody else to take care of them, because the philosophy was still you do everything the same in whether they're dying

> or they're not, and you get them up, and you move them. The hospice philosophy even in a care center has changed it to a point where you look at it as comfort only, and there's no schedule, there's no set time to get up, no set time to eat, it is on the patient's ability and desires, and they then become the boss in effect of what's happening to their life. It's not people doing things to them, or doing things for them that they want. And that's the hospice philosophy, it's that they are the one's that need the care, and the care is geared to their needs, not anybody else's needs.

Nurse 1, when describing comfort care said that, "Everyone is different, some people would rather be in a little pain and not be sleepy, others are happy to be sleepy. That's why it is important to find out on the first visit, find out what they want." Nurse 5 talking about what her priority of care would be, refers back to the patient,

> Well I kind of look at again quality of life and when I usually go in and I'm getting to know a family and my patient I'll just tell them …. "What we want to do is make your life as good as it can be, for as long as it can be," and then I ask them what is important to them. You know, what do I need to do to help you get there in the time you have left, what's important to you, and how can I help it be the best it can be. And so then I'll just kind of design my plan of care around what their goals are, which always includes symptom management because if you're in pain and if you're nauseous and vomiting or if you are constipated or have diarrhea, you are not going to have any kind of quality of life. So that's one of the things that you have to focus on, and then just going from there and getting to know them.

The concept of a good and bad death was also mentioned in relation to patient goals by nurse 4, who gave this definition of a good death,

> That's defined by each one, each patient is different, and my goal would be to find that out early on and help them to work towards that…not reaching their goals is not a good death, but reaching their goals would be a good death…. what ever they are, and everybody is different.

Comparisons Between Hospice Nursing and Other Nursing Settings

Two of the nurses had very recently worked concurrently in both hospice and acute hospital settings. For these 2 nurses, describing hospice philosophy was

best done by comparing the two settings. Part of the interview with nurse 4 is included below, where the respondent compared hospital and home deaths as "good and bad deaths,"

> My idea is, I guess, making however much time my patients have left as good as it can be. And so I have seen because I worked in the hospital for a long time before coming to hospice, I have seen good deaths and I have seen bad deaths, and I just think that the life up until it happens should be as good as it can be, and then the death should be as good as it can be. And so that's my philosophy.

When asked to elaborate on the idea of good death versus bad death, Nurse 4 elaborated,

> A bad death in the hospital is when you know, you've got this 92 year old/ 96 year old little old lady that the family isn't willing to consider you know a DNR (do not resuscitate order), that kind of thing, that she ends up getting coded, her little ribs are cracked her life is…. you know she's intubated, it's a horrible thing and then in the end she dies anyway. And you know if you've ever been in a room, which you probably have, that's just had a code in it, it looks like a war zone, and, death doesn't have to be a war zone, you know. A good death would be if you have accepted it and you don't want any more treatment and you don't want any more chemotherapy and you don't want anything else to be in charge of your own destiny and to be able to be as comfortable, surrounded by the things the people be in the place you want to be, be as pain free as possible and to have as good quality of life as you can have until its over.

Nurse 3 also describes the differences between hospital and hospice care,

> Hospice philosophy is very different because it's a palliative versus a curative style of treatment. I think it's needed, I think it very much should be encouraged. Patients and their families after they receive curative treatment but they have no longer any options open to them and they need a place to go and I think hospice picks up that leftover piece, of where… OK, you for example have cancer, you've done your chemotherapy, you've done your radiation, you've done selective surgeries and now they've presented to you, you have a particular type of cancer that's advancing regardless of the chemo and the radiation treatments, therefore there's nothing more beneficial that we can do for you, we can keep attempting; and you can be losing your hair and vomiting and have all these side effects from what we're doing, over the next three months until you die, or you know you could go to a hospice idea where you can stop the treatments knowing that… foreseeing the future in a way that there's nothing more that's going to be

> done, eventually you are going to pass away and you can still be at home you can still be with your loved ones you can still be comfortable without doing the needed hospitalizations, and the continued chemotherapy and the continued radiation and that kind of thing that causes bad side effects. I think that hospice picks up where curative therapy says I can't do anymore, hospice says, 'well we can help you'.

Acceptance of Death

One of the differences between hospice and other nursing was the acceptance of dying, Nurse 1 stated, "In hospice you can talk about death openly, in other situations even in homecare when the person is seriously ill, you never talk about death. No one ever wants to talk about death, I don't know why not." Nurse 5 offered an explanation, in the following narrative;

> Then, at the very end the doctor might say Ok we'll call in hospice. Like we're the death squad or something as opposed to nurses or a team that can help make life better. You know, to me hospice isn't nearly as much about death as it is about life. I mean we're all terminal you know…but you know but a lot of that is I think our whole medical system. We're in a curative model and I think a lot of doctors and you know and nurses as well see death as the enemy you know, and its not always the enemy and they see it as a defeat, as opposed to just transitioning to a different kind of care. You know it doesn't mean you are not going to care about your patient any more, it just means you're going to do it differently.

Nurse 3 continues to compare the two types of nursing, talking of the experience of working simultaneously in hospice and ICU. He felt, however, that there are merits of both aggressive and palliative treatments,

> That's a mix, its completely the most aggressive curative therapy that you could possibly… you know I mean I can't think of anything that's higher intense care than an ICU level of nursing, and yet you've got an ICU nurse one day doing a PRN shift in the hospital, doing an ICU shift, placing a PICC line, running a ventilator, and talking with doctors about how to get his blood pressure up and what we are going to do to fight the rampant infection that is going to take his life by the end of the week, and there's nothing we can do about it but doing everything we possibly can, and then I leave there and I put on a different shirt, I have to work the next day as a

> hospice nurse. And that patient with a rampant infection needs pain medication. He's to be extubated and he's to be at home where he can say good bye to his family, instead of dying in a hospital where it's limited access…where he needs to be comfortable.
>
> Asked about whether this was frustrating, Nurse 3 replied,
>
> The frustration can go both ways. The frustration is I have seen patients here on hospice where I thought that they could really benefit from some intense therapies, but I have seen patients in the ICU receiving intense therapies where I think they would have benefitted more from hospice… patients die in the hospital every day, patients die in hospice every day, so patients die regardless of their setting. Sometimes dying while performing CPR gives comfort to the family that they've gotten everything they possibly can and that they've done everything they possibly can do for that patient, for that loved one and for others bringing them home to hospice, we've done everything we can but he's home and where he *wants* to be and he's going to die where he *wants* to be, with his family around him, that's the important decision for them.

Family Care

The one feature of hospice nurse philosophy that was mentioned by all of the respondents was that hospice care was care of the whole family. This care was seen as ongoing extending after the loss of the patient. Nurse 5 explains, "…in this work the family is almost sometimes as integral a part of the whole situation as the patient is…" Nurse 6 describes working with the family, "So, it's a lot of education for family, and a lot of listening, a lot of just feeling their fears, and listening to them, and trying to help them cope with what they're feeling, and that's a big part."

Hospice Nursing

A Good Fit

That the nurses as well as other hospice workers used their own attributes in their work was indicated in several comments for example, "different life

experiences come into play," and "you need different people's perspectives." Several of the nurses were keen to add how much they enjoyed their job. The 3 older, more experienced nurses, with longer nursing careers, all said that it was the most rewarding field they had worked in. Two respondents used the words, "a good fit," referring to their personal suitability for the job. Nurse 4 spoke about this,

> Yes, I feel like this is 'the way', that this is the part of nursing that I have enjoyed the most and I have worked a lifetime to find this and I feel like it fits me like a glove. And I think I do a good job at it, I think I enjoy it, and I can, I can make a difference... I just love it and I don't think, I mean I've been at it 9 years, there are times that I think are harder, but I'm not going to change, I'm going to continue to do this as long as I'm enjoying it and I have enjoyed it more than anything I've ever done.

Nurse 6 echoed this sentiment and describes the nature of the work that make it a "good fit" at this time of her life,

> You know I think the only other thing that I could say about hospice is it has been for me a great, great fit at this time in my life. When I came to hospice I found a place where in my last years before retirement I could find some real peace to what I did, and I think that's the biggest thing I've found in hospice is sense of peace, um.…and it just there is such a peaceful demeanor among the workers, at least 90% of the time, that we, that we just find that it's peaceful to walk into the office and peaceful to walk into the homes, because our nature is geared towards peace and comfort, little bit different, and for me at this time of my life, that was just exactly what I needed...I needed a place where I could just find a little peace and a little comfort and still be able to do my work and it has fit perfectly for me, and I love it. It was about three months after I started hospice that I remember coming out of a patient's home and I was at my car getting ready to get in and I remember looking towards heaven and saying "Why do I enjoy this so much? You're not supposed to enjoy death and dying," it is illogical, but I found I really, really enjoy the work and it was where I needed to be.

Spirituality

Although I did not question the beliefs of my respondents, their spirituality and respect for the spirituality of their patients came across in their descriptions of

"death as a sacred time," and the way they spoke about death as "whatever they believe is the next life." Only 2 nurses expressed directly how their own spirituality and beliefs were part of their work. Nurse 5 speaks about how her beliefs influence her work,

> I look at hospice and nursing in general as trying to be an extension of my faith and although I don't use it as an attempt to proselytize or anything like that I look at it like um being God's hands and God's eyes, and hopefully they'll see that kind of love reflected in my eyes and in my hands".

Nurse 6 wove spirituality into most of her narrative, she was also aware of not imposing her own belief on others, "Religion doesn't play a part in what we do, it's going where the patient is spiritually, [which] doesn't mean religious help, unless it's going with them with their own religion and what they are telling us." She mentioned the added spirituality she has gained from working in hospice as her greatest reward, "just the things that I have done or the patients that I have worked with have given me some great spiritual insight myself into what happens at this time." She also felt it was important that "nurses understand their own spirituality and how they bring that to the table to help when it comes up not that that's the prime reason for going out, but in essence you turn around and really it is, because we all have to address spiritual and social issues." Most of the nurses felt confident, (in varying degrees) in meeting the spiritual needs of the patient, but this was an area where they all acknowledged and were grateful for the expertise of the chaplain.

<u>Stress</u>

I asked two questions of the respondents; "What is the hardest part of the job?" and "What is the most stressful?" Issues having to do with repeated loss, grief and suffering were responses to the hardest part of the job, but were not necessarily considered the most stressful. After talking about the emotional toll that hospice work can take, respondents were asked whether this was the most stressful part of the job. Nurse 7 replied,

> Not necessarily, no, the stress comes in trying to make sure that you're doing everything that you need to do. That you are covering all the bases and you're that you're documenting everything; the highest stress comes when you, when you question yourself as to whether or not you have done everything you can do. [Pause] No, the emotional is stressful but there are more-- there are greater stresses in the job itself.

Time To Do the Job Properly

Lack of time to do the job properly, or as they would like was a common theme, Nurse 4 talks about this,

> No the thing that stresses me most is um [pause] too many 'pullings' on me, if I can focus on one thing, and complete it and do it right, then I, I feel that that is the best, but when I'm being pulled here and pulled there and pulled and everyone is needing a lot then that's when I'm stressed.

The common phenomenon of patients being referred late into their disease was cited by nurse 5 and its effects on her as a hospice nurse described,

> I wish that people would come into [hospice] sooner; I think, you know, I was thinking when you said you know what was the stressful. I think one of the most stressful things is where people come into hospice *so* late and you don't get the time to make, to prepare the family like you know I've had patients when you're involved in their lives for five or six months, by the time um the patient begins to actively die you have a relationship, with the patient and with the family you've got things smooth, you've got things under control, and it just makes for an easy transition because you've had time to make it so, but what's really hard is when people are actively dying and they call in hospice and its like, really? Because you don't have time if the patient is already actively dying you are not going to be able to have a

> relationship with them, you don't know them very well and the family is already now at this high level of stress and its just they don't get the full benefits of hospice and palliative care but I think a lot of that again people not wanting to accept the situation until it is too late. It often happens in facilities where patients are in a facility and then um at the very end the doctor might say "Ok we'll call in hospice"…. so that's a frustration and that's a hard thing, and I've had way too many of those where you're going in and you want to just go "Really? Really, people?" So I think that's one of the things….when I've seen people go into hospice earlier it's a better experience.

Not Meeting Expectations

When asked "Are there stressful parts of your job?" Nurse 6 answered an emphatic, "Yes," going on to say,

> There are some very stressful parts. It's when you cannot get a patient's pain or anxiety controlled. That is the most stressful I think for me….the pain issues are mine to deal with and it is really hard when the patient's family is saying *please* can't you just get him out of anxiety, and you've tried this and you've tried that and you've been back and forth with the doctors, and it really is not something that you seem to be able to control and day by day its not controlled; it is very disheartening as a nurse to think that that's what I'm supposed to control and I can't get it controlled. And you go home saying, "Why, why can't I get this controlled?"

Not meeting their own expectations of providing the best care possible was coupled with not meeting the expectations of the families they were working with. Nurse 5 describes this,

> Some families are more difficult to work with than others and are more um you know, you get to the point where you have certain people that you see the number on your phone and you just want to go "oh no," [laughs], and often you know its not the patient it's someone in the periphery of their life or whatever but [they] think that you can make everything perfect and everything….and they want things that just aren't in the realm of reason, sometimes.

Nurse 1 mentioned the stress that the family is experiencing being directed towards hospice nurses, "Sometimes everything seems alright and then afterwards

people can get angry and take it out on hospice." Nurse 3, the on call nurse, alludes to anger directed towards the nurse coupled with the frustration of an unknown situation,

> One of the harder aspects is that I don't know what I'm walking into, being on call. A family calls me and tells me mom or dad doesn't look good, but that doesn't tell me what's going on. It doesn't tell me that the patient fell a couple hours ago and now is in excruciating pain, and that the family is in crisis mode, and they are ready to kill me.

Frustrations between nurse and family it seemed could run both ways, nurse 6 mentions her frustration with the family of the hospice patient,

> Then of course it's some of the family members, the other stressful thing is when a family member is refusing to give medications that you're offering to a patient and you know that that will help the situation. It's OK if it's the patient's desire, that we can understand and we can live with, but it's when the patient has a desire for medication; something to alleviate the pain and the family doesn't want to give it, because they think there's a problem with it-- that they're going to die tomorrow if they get it. It's again education to the family members, but it is disheartening when even with education sometimes they'll say "Well I just don't think he needs it" and yet you watch them stay in pain or anxiety because they don't get it. That's very stressful.

Feelings of not being successful in controlling symptoms were often cited as the hardest part of the job. Nurse 4 answered, "Not really being successful, seeing that no matter how much you do or how much you see needs to be done, that they still don't have a good death, that's very hard for me." Nurse 2 also refers to suffering that she can't control,

> I would say probably just watching patients suffer, you know, and patients who aren't ready to die. I think that's really hard to see. You know just because it's really sad, you just feel really bad for them and patients who really haven't had the best life or haven't had as much life as they wanted and just haven't been able to cope with it yet-- how to cope with dying. Anyway, it's really hard to see, because you can only do so much as a nurse you know. You can't change their state of mind you know, so that's probably the hardest thing.

Two of the respondents mentioned dealing with loss and the accompanying grief. In answer to "what is the hardest part of the job?" nurse 5 replied, "Um … [pause] all the losses you know you grow to love these people you know…. and so I do give my patients a piece of my heart and so when I lose them it's hard and I grieve." Nurse 7 added,

> The emotional, the emotional roller coaster that it puts you on, when you, when you have a patient that you become quite attached to, and then when they're gone then you have to deal with that loss…. that's the hardest part.

Coping Strategies

The need to be able to cope with the challenges of hospice work was recognized by most of the nurses. Nurse 4 acknowledges these difficulties,

> I know they say you can burn out, and there are times when I have felt that I just can't take one more step, because it is a little difficult, I think it is a really difficult thing at times, but on the other hand I can shrug it off and still be there for people.

One nurse mentioned that her personality helped,

> Yeah, I'm kind of a …not really a high stress person, I'm pretty laid back so I don't really let it stress me out too much, you know I worry about patients and I have my own way of coping with things that I don't necessarily get stressed about it.

Although this nurse did not elaborate on her own way of coping, two of the other nurses explained their methods. Nurse 5 describes her technique "I grieve and then um I kind of over time let it flow through me and then um just go on again, do it all over again so I think that's really hard." Nurse 6 reports using imagery:

> I've learned how to distance myself when I need to be distanced from it, I kind of have a doorway in my mind that as I go into a home, that their door is open to me and my mind door is totally open to them. I do everything I need to while I'm in the home but as soon as I walk out the door, and I know that everything I can do at that time is done, my mental door closes. I've

> found putting on my book tapes and listening to my tapes gets me kind of into another realm. If I get a phone call its like a big window opens up and I'm right there with them, as soon as everything is done that I need to do, that window closes again, and about the only other time that something opens is at night time when I say my prayers, they're all in that little porthole there, but it's the way I've been able to do this work the way I do is because I do have a family and I do have a life and mine can't coincide so much into theirs that I have to live their lives when I go home as well. I have to live my own life when I go home, and that's how I've been able to do it."

Nurse 1 also acknowledged the tendency to take the work home and recognized the need to live her own life,

> Sometimes it's hard to leave work behind. If I have a patient who is actively dying then I think of them when I'm not here. I worry for them and wonder how they are doing and hope that everything is going ok. Then I have to think no, this is my time to spend with my family.

Rewards

Although one of the questions I asked respondents was, "what is the most rewarding part of the job?" 5 of the respondents mentioned this topic spontaneously after describing the hardest part of the job. Nurse 2 observed, "You meet the nicest people, you really do and people that are so grateful for all, for what you do and um that's the rewarding part." Nurse 7, after talking about dealing with the loss of a patient said,

> That's a double edged sword because the best part can be the feedback and so on that you get from the family and the appreciation that they show for the help that you have given… it's the most rewarding thing I've ever done--it's also the hardest.

Being appreciated was also cited by Nurse 5, who uses a scenario to answer the question, "What do you find most rewarding?"

> One of my very favorite patients was pretty complicated and the family also had a lot of things, well over the weekend some things had happened and when I came to the house on Monday morning his wife said, "Oh honey the

> nurse is here". She said "Now that you're here everything will be OK." And you know its just that kind of feeling when people give you that much faith, and that much confidence you know and just that feeling that you know, "We can do this and you'll be able to help us make things better" …. It's such a nice thing you know…. I feel that's really rewarding and it's such an intimate thing, and I was always prepared for the physical intimacy you know of nursing …. but it was the emotional intimacy that surprised me its such a unique relationship….I think that's why people trust nurses so much is because its just this relationship where I just want to make your life better, I want to help you as much as I can and you know the flip side of that coin is it ends up making your life better too. You know, it ends up that you're feeling better at the end of the day and at the end of a situation….It's lovely after someone's passed away and its been a good death and its been a good experience to have the family look at you and say, you know, "Uh, we couldn't have done this without you, and how great it was and he was so happy and we were so glad he was able to stay at home and we…" you know, that's very rewarding, it's very rewarding. And the cards and the letters and that kind of thing, it's really meaningful I think, you know, things that are more important than your pay check! [Laughs].

The gratitude of patients, as well as the feeling that to make someone else's life better was reward in itself was reiterated by Nurse 2,

> You meet people that are so grateful for all, for what you do, and um that's the most rewarding part. For sure, just to be able to make somebody's life when they're so stressed and they have so much going on, just to make one thing a little easier for them, it's so rewarding.

Interdisciplinary Team Working

Interdisciplinary team work was deemed essential to all of the nurses interviewed. Holistic care, with its physical, emotional and spiritual domains, was reported as better addressed by a whole team of specialists. Most of the nurses' comments alluded to their deficiencies in addressing spiritual issues, and appreciated the input of a chaplain. The on call nurse felt at a distinct disadvantage not having access to a social worker out of hours to help address family problems. The nurses generally felt able to offer some support in all of domains of care;

physical spiritual, psychological and spiritual (although they expressed varying confidence in their abilities), but acknowledged their limitations and were grateful for the expertise of the other team members. For some respondents, the roles of social worker, chaplain, bereavement coordinator and other members of the interdisciplinary team seemed to have very defined responsibilities; for other respondents roles seemed blurred.

As a Support to Families

The general enthusiasm for the interdisciplinary team can be summed up by Nurse 2,

> Oh I love it, I love the team. I think it's a great idea to have all the different people, social work and chaplain, I mean families really need it even if they don't think they do, [laugh], I think that they need all of these different disciplines when it comes to a death in the family, so I love it, I think it's great!

Team Implementation of Holistic Care

Some nurses acknowledged that although there was an interdisciplinary team, it was the nurse's responsibility to address more than the physical domain of care, although many of them felt that as a nurse, physical care was their main responsibility. Nurse 7 stated, "So, although the nurse will predominantly be going towards, er pain control, er that sort of thing and keeping that kind of thing under control, the nurse is also responsible to make sure the other areas are addressed as well." Nurse 6 felt that nurses should be able to address all aspects of a patient's care, "it is not a good justice for a nurse to say that's not my area, I don't talk about

what the social worker does, we all have to talk about that with whoever is having a problem at the time." Acknowledging limitations, Nurse 4 explains at what point she would really need the team,

> It's a team approach but I never say that I can't do something that is that I feel comfortable with and you know when you get experience the team kind of merges like this, (knits hands together). But I think that, I don't feel, I'm definitely not trained in doing spiritual, I'm definitely not trained in doing emotional, and um those kind of things but I do feel that with the experience that I have that I can add to that, and then if I feel overwhelmed, I can bring in other people.

Nurse 6 said, "When they're really hurting, they're really having struggles, then I think it's really important to bring in your team members; the chaplain, the social worker that's what they're really geared to being able to do." Three of the nurses felt that just having another person to call on, to relieve them, to add another perspective or validate what they had said to a person was valuable no matter what the person's discipline. Nurse 5 illustrates this perspective with a story,

> When it becomes too much…. I mean, it's sometimes just too much pressure, for example I had a patient the other day, and she called me oh probably two to three times a day and I could hear the tension in her voice, I could hear the stress in her voice, she's clearly not come to terms with her 96 year old mother's advanced dementia and I could hear the tears just behind her voice you know, and she was just so high strung I could tell she was just ready to lose it, so I spent a lot of time with her on the phone, over a couple of days and then I was able to call [the chaplain] and say "Could you just give this gal a call? I think she just needs to talk things through" and sometimes just hearing or having people kind of just say the same thing in different ways, helps you know. So [the chaplain] was able to just go you know and just be a sounding board for her and hopefully sometimes people can present things in a different way that help you come to terms with things and just offer more support, and offer maybe some balance you know from having different people's perspectives and different people's own life experiences coming into play.

Even with the interdisciplinary team roles it was acknowledged that holistic care is difficult to separate into domains. Nurse 4 spoke of this,

> I can't draw a line between it because the physical is very much dependent on all of the other um what's the word I want, the other things that are done, you know the spiritual, mental, and all because I just can't, I just can't separate them.

Nurse 6 talked about how a stressful situation, in which she felt she was unable to do what she saw as "her job" (managing pain) was helped by calling in the chaplain in the following narrative;

> That is the most stressful I think for me, I can see the spiritual issues, but I can call for someone else to come in if they are really stressful that way, but the pain issues are mine to deal with and it is really hard when the patient's family is saying "please can't you just get him out of anxiety", and you've tried this and you've tried that and you've been back and forth with the doctors, and it really is not something that you seem to be able to control and day by day its not controlled…. and yet you're doing everything the doctors give you to and it does take time sometimes…. like for the patient we've had recently, there doesn't seem to be anything ….until they spiritually, with the help of the chaplain, can get things squared away to where they understand spiritually that they'll be ok as they go through this process. And when they finally reach that it's like the pain seems to subside at the same time, because the spiritual pain is subsiding.

Vital Signs

Respondents had mixed ideas regarding taking vital signs although they all could see relevance in doing so at some part of the patient journey. The reasons for taking vital signs could be divided into two main categories: monitoring physical status and perceived psychological benefits, particularly for the family and the nurse.

Monitoring

Taking vital signs with a view to manage the patient's condition was seen by most of the nurses interviewed as being more important in the early stages of

disease progression than the later stages. Nurse 2 felt that if a patient was stable in the early stages, she would not have to take them a every visit, but she and Nurse 1 felt that they would still do them once a week. Nurse 3 specifically recognized that the need to take vital signs was not essential because, "Vital signs would give me indications of what is going on internally, but if we look at the end, the patient is going to pass away." This same nurse also felt he needed to do it as the doctors often asked for this information.

Symptom Management

Three nurses saw taking vital signs as necessary for symptom management particularly measuring the blood pressure to screen for hypotension related to fall risk, and for medication management, specifically of diuretics and anti-hypertensive medications. Most nurses felt the vital signs were an important indicator of change, "It helps you pick up changes, then you can see if it is something to fix or is part of things." Vital signs were also mentioned as being able to help identify pain and dyspnea.

For the Nurse's Benefit

In response to my inquiry, "Would you always take vital signs?", Nurse 7 replied, "Always have," and Nurse 4 stated, "It makes me feel that I have done the right job ….I always do them." When asked "Is there a time when you would not take them?" 1 nurse endorsed the idea of taking them right up to the end, answering, "No not if they've died er then you don't have to take vital signs to determine that."

Asked if there would be a time other than this that it could be waived, the answer was, "Um, I can't think of any." Reasons to routinely take vital signs varied, "it's just a part of my assessment in general, I do a head to toe assessment every week, so I'm not going to not do vital signs, because it's part of my assessment." I had already observed that the weekly patient assessment form that is required by the agency on each patient has spaces to record the vital signs, so there is an expectation that this be done at least once a week.

For the Family's Benefit

Almost all of the nurses interviewed felt that they were taking vital signs on the patient for the benefit of the family, usually mentioning that it was reassuring to them. Nurse 4 speaks of vital signs being of benefit to both her and the family, alluding to the psychological importance to both,

> [Vital signs are] imperative, really imperative. And sometimes I have to say that it isn't just for the patient or for the information that I get from it, which is critical I think, but it's a way of getting in and doing the other stuff. You know the family can see you doing that and a lot of mine is a verbal question and answer kind of thing, but I like to lay my hands on and do a good assessment not just vital signs, but laying on of hands and feeling things, and it makes me feel like I have done the right job, and I get good information from it but it also lets the family know that I am going to turn over every leaf to help them.

Often it was perceived to be more important to the family of the patient than to the nurses themselves. It was frequently seen as an indicator of patient health status, or a decline towards death. Nurse 1 explains,

> Sometimes the patient's family want to know what the oxygen SATs are and then they can know if they are going to have a good or bad day, but sometimes I don't like to tell them, because then it can make it a bad day [for the family].

The idea of using vital signs as a predictor extends to the very end of life. When asked whether you would take vital signs even in the "active dying" stage, Nurse 4 answered,

> Absolutely, and the reason I do it is for the family, because they always are saying, "When? How long?" and the vital signs are really the ones that are the indicators. You know there are other things that you look at, and I just like to go through them and to people I say, "OK, blood pressure's down, pulse is up, SATs are down, breathing" and then I explain the breathing that I've seen. Then I talk about are they going to be, they are going to be withdrawing, and their level of consciousness, all the things that I have noticed and I teach the families because it's a comforting thing for them to be able to see, and be able to recognize those signs as well, cause no one likes to have a surprise at the end of it.

Another nurse felt that doing the vital signs could enable him to "alert the family if the time is short may be within hours."

In an interview with a practicing Specialist Palliative Care Nurse at the University Hospital, I asked for her views and experiences regarding the routine taking of vital signs. As an advanced practitioner coming to palliative care from quite a technical background in cardiac care she explained her initial feelings and how these had changed over time,

> Initially when I started in palliative care I strongly felt we should not be doing vital signs at all when people were actively dying, that we were disturbing them, by taking temperatures, we had to manipulate arms for blood pressures. It didn't make a lot of sense, and then several families said, "Why aren't the nurses coming into the room anymore? We feel like we are being abandoned," so that was one thing. Another person said, "What's the blood pressure? We've been following mom's blood pressure for years, this is how we've always gauged how mom is doing, and we need to know how close she's getting to the end of life." I've had another family member say to me, "if her blood pressure's low and it continues to drop wouldn't that give you an idea that she's getting closer to the end of life." So what I came to learn is that a lot of families really use vital signs as a way of gauging how much time is left. So we decided to meld both approaches so on our team vital signs are done twice a day. Once in the morning and once in the evening and that's it. And if families say we don't want vital signs taken

> any more they are discontinued. But on our standing orders we have vital signs written twice a day.

The advanced palliative care nurse then offered an explanation to why the families place so much importance on the taking of vital signs,

> I think its because every time you go to an out patient doctor and in the clinic, every time you come into the hospital, especially if you are in the intensive care unit….you see your family member's blood pressure either being taken every two hours or they have an arterial line in and the blood pressure is just displayed on the screen. So every time a family has walked into an intensive care unit the first thing they do is look up at these numbers, they want to know what those numbers are because everyone seems to gauge things by the numbers. So to be able to go to a setting where all you have to do is look up and see a screen and see what the blood pressure is to go to a setting where you never know what the blood pressure is at all is sometimes a really hard jump for families to make.

This Specialist Palliative Care Nurse also went onto elaborate on a point that had been made by one of the hospice nurse respondents, that it is a way to get in and do other things,

> There are some nurses that are very uncomfortable with end of life and will do everything they can to avoid from going into the room because they don't know what to do, and they don't know what to say. So by writing an order to have vital signs done twice a day I know that the family is going to be able to see that the nurses have been going in the room. I have gotten the feeling from the family that if the vital signs aren't recorded they are saying…. "Is the patient just in here to die, are you abandoning them, have you just closed the door, and the nurses don't even come in and check on them," which is where we do a lot of education for the family about what the new goals are now. That just because a blood pressure isn't being taken every two hours doesn't mean we are not caring for the patient. It just means we are looking and doing other things for the patient.

Taking Vital Signs Is not Always Necessary

All nurses however, acknowledged that vital signs were not always a reliable indicator, and certainly not the only indicators of impending death. Although 1 nurse said that "vital signs really are the ones that are the indicators," if a patient did

not want vital signs performed, the nurses felt they would be as able to tell how close they were to death. Breathing was cited the most often as a more reliable predictor than vital signs of a patient's decline. Breathing changes described by the nurses included rales, gurgling, Cheyne-Stokes respirations, and periods of apnea. Nurse 6 explains, "When their breathing changes….those are really the signs, the blood pressure really isn't going to tell me when or how close, except that, yeah, they're in the dying phase. So they can be helpful to me, but they're not what I look at the most to know that someone is going."

Nurse 5 recognized the possible repercussions of an over emphasis of vital signs, and had formulated a method for weaning the family away from over reliance on them,

> I don't want my families focused on you know decreasing oxygen saturations, and that kind of thing, and decreased heart rates and that, I want to give them more things they can look at themselves and see, and once they are dying to me that's like sacred time, and I want to give them other things to focus on rather than numbers you know and that kind of thing. Well I will, [take vital signs], if they ask me to you know. But once a person is there a lot of times I've said to people "Well, if you really want, lets do it once, and then after that maybe it just won't matter all that much any more," it's kind of where I'll try and help them get to you know.

When I questioned the Specialist Palliative Care Nurse regarding the necessity of taking vital signs she said, "Do I think it's needed? If I had a family tell me I don't want blood pressures taken, I would say that's fine we can use other signs that the body is trying to tell us that when they get closer to the end of life."

I also asked the Advanced Specialist Palliative Care Nurse if she felt vital signs were a good predictor of end of life,

> [Sigh], I think it can be a part of the prediction, or part of the prognosis, definitely. It's not the only part and you don't in my opinion, need it to

> make a prognosis. If a patient loses peripheral pulses both radial or dorsalis pedis pulses and you can no longer feel those pulses, it is usually a predictor that the patient has a life expectancy of two to four hours, so and that is because the patient is so hypotensive that they have clamped down on their vascular bed to bring all the blood back to the vital organs. So that would be a pretty good indication that the patient's blood pressure is pretty low, um so I think that it can be part of the prognosis definitely. I think if somebody told me, if the nurse comes to me and says a patient is supposed to be transferred out to home, but we can't get a blood pressure on them if we've checked a blood pressure and its 60 over nothing, this is not a patient that I would let leave the hospital, I would suggest that we would keep them here because I would assume that their death would be imminent. So I think there are some specific settings that it can be helpful.

Documentation

Most of the nurses interviewed felt that the required documentation was excessive, and three of them mentioned documentation in reply to the question, "What are the most stressful parts of the job?" All of them, however, realized the importance of documentation. Nurse 4 probably sums up the feelings of most of the nurses in her statement, "I think documentation is an important thing that I don't care to do, and yet I think it's important."

For Legal Reasons

All of the nurses recognized the importance of documentation for legal reasons. The most basic explanation was given by nurse 2, "If you get sued, by a family member or something, you want to make sure you have the documentation that you did what you were supposed to." It was acknowledged by some of the nurses that hospice documentation had particular importance as far as legalities went. The comments of nurse 6 are illustrative:

> I think documentation is really important, for one thing that we're doing a very, very vital work. And sometimes because of the kind of work we do, somebody could misconstrue it as doing something that maybe we shouldn't have done, and it is really important that you document things very carefully, so that you are always protected as a nurse, so it's always been my philosophy, that I make sure that everything that has happened, especially if it was something that was uncomfortable was documented totally in what I did, and how I did it, so that I'm covered. Its kind of what I call covering my back, so that I know that if ever it came up, somebody said no, she didn't do this right, my documentation would prove that I did do it right. I think that's important for me, but I think it's also important for the patients, because it proves that they were given the kind of care that they really deserved. If I have a patient that had a struggle with spirituality, err, they're saying things, I like to include that in specific quotes… because it shows where they were at the time that I decided they needed that medication that I gave, because they were really hurting, or that they said, "Please, I need more," those kind of comments [written] in quotes show the reason why I make the changes that I make. And so it shows that they are getting the quality of care that they deserve … these are people's lives that we are working with, and they deserve to know that we have done things correctly, and that's the way that we prove that we did.

Within the theme of taking vital signs for legal reasons, 1 nurse also felt that the documentation was a way to prevent fraud within the hospice care industry. Although they recognized the importance of documentation for legal reasons, to some nurses, the amount was tedious, much of the information had to be repeated, and "On two or three pages you are writing the same thing." Another nurse added, "I think there's a lot of stuff that is just driven because it's a bureaucracy you know." Nurse 2 suggested that it could be streamlined using computers,

> You know I get frustrated a lot because of all the paperwork, that I think can be a lot simplified if we had computers you know, so that the only thing that frustrates me is not that I have to do the documentation cause it's very important, we need to do it, it's very, very important, but I think there's a simpler way to do it [laughs], well I don't know, I'm not even looking for simpleness really, just more efficient.

Need for Narrative

Three of the nurses recognized the importance of having a space on the documentation for a narrative. Nurse 7 explains,

> Here in hospice work a lot of our paperwork is a checklist, but there is, it's important that there is room for some documentation outside the checklist, er so you got both of those sometimes just the checklist approach can miss a lot of stuff.

Nurse 6 mentioned the importance of being able to document spiritual issues, "If I have a patient that had a struggle with spirituality, they are saying things, then I like to include that in specific quotes."

For the Nurse's own Benefit

Before 2 of the nurses mentioned the legalities of documentation, they mentioned it being important to them personally. Nurse 2, "You need a record of what you've done, for yourself to be able to look back, and see what you've done." Nurse 4 added, "it gives me a place to look at and say 'oh this is what I saw before,' because I don't want to get mixed up, I want to be sure that I can fall back on it."

As a Communication Tool

Two of the nurses noted the significance of documentation as a communication tool, as Nurse 2 explained,

> It's important to be able to document that to make sure we're all on the same page, and that anyone can come in and read what I've written, and know if they were to cover me, know what needed to happen the next time, or the things to look for and also for other caretakers of the patient to be able to come in and know what has happened.

DISCUSSION

In this study, I set out to explore the beliefs and practices of hospice nurses in Utah and to determine what philosophies and systems underpin their practices and the care they provide. I also specifically sought to discover their views regarding the taking of vital signs, documentation and the merits of interdisciplinary practice.

The idea that American culture may influence hospice philosophy, and in some instances it override it, initially seemed substantiated in part by the routine taking of vital signs, despite most nurses agreeing that doing so was not necessary as far as directing treatment, or for providing comfort care to the patient. Because hospice philosophy includes care of the family however and part of the reason for taking vital signs given by the nurse respondents was to reassure the family this could be seen to support hospice philosophy.

Hospice Philosophy

The hospice philosophy as articulated by the respondents included care being comfort oriented rather than curative. Hospice was viewed as an environment where death could be talked about openly. The concept of a good death was equated with hospice care, although it was recognized particularly by the 1 nurse who had also worked in acute care that some people may not choose hospice and

may choose to have everything possible done to keep them alive. Similar to Evans and Hallett's study (2007), the nurses mentioned relief, peace, and connected comfort with spirituality. The nurses in my study also connected comfort to support, helping them through the last stages of their lives. Dignity was also seen as an important aspect of care linked to comfort. Comfort was also perceived as being surrounded by the things and people that had meaning for the patient. Being as pain free as possible was also seen as providing comfort care. One of the nurses mentioned that comfort meant different things to different people.

Hospice philosophy for all of the nurses interviewed included a strong element of patient choice. It was important to the nurses that the patient felt in control. Listening to the patient to find out what could be done to enhance the time they had left was important to the nurses, then establishing goals that took into account both the patient's desires and abilities.

Hospice Nursing

Some of the stressors mentioned in the literature were identified by the respondents in my study, others were not. In the metasynthesis by Kehoe (2006) cumulative losses, intense emotional situations, stresses relating to respecting autonomy, and the need to accept situations in which one cannot bring comfort were cited as potential stressors for hospice nurses. Struggling with a health care system that cannot or does not meet all needs and expectations, with limited resources, and myriad stressors embedded in the health care system and human to human interactions, were also identified as stressors (Kehoe, 2006). These were all

mentioned by the nurses in my study in the context of not having enough time to do the job properly, or to the best of their ability. That effective comfort care takes time to achieve was consistent with Evans and Hallett's (2007) findings, specifically as time to develop a sense of trust with patients and their families.

Not being able to control patient's symptoms was a very common concern, as was failing to help people reach their goals. The nurses I interviewed identified similar barriers to providing effective symptom management: the family not being able to implement or maintain treatment, and the patient or family not wanting the treatment as Johnson (2005). These reported frustrations with family were particularly hard for the nurses to deal with when pain control was the issue.

There was no mention of problems with management or feelings that other staff members were not doing their job in the interviews I conducted, in contrast to Martens' study (2009). My findings were more in harmony with those of Payne (2001) who concluded that despite the difficult nature of hospice work, "The positive atmosphere of the hospice, with its holistic approach to care, its supportive interdisciplinary team and low levels of staff conflict may make it a positive environment in which to work" (p. 404). Paperwork was cited by the respondents as stressful, in line with Kulbe's study (2001).

Coping

One nurse in my study felt that her personality helped her deal with stress; 2 others specifically mentioned the ways they had managed to cope with the stress, 1 by "closing it off in her mind," the other by "letting it flow through her." Nurses in

Mercer and Feeney's (2009) study talked of being "detached to a degree" which could be seen to describe these coping methods. It seemed from their conversations that despite trying to "switch off," they did think about patients when they were at home. The nurses were however striving for this work/home balance. The respondents also referred to colleagues in the multidisciplinary team as being a support, as was the peaceful nature of the office; these mechanisms mirrored the findings of Ablett and Jones (2006).

Rewards

All of the nurses I interviewed felt that hospice nursing was a rewarding job. Olthius et al. (2007) suggest that although hospice nurses aim to improve the quality of life of dying patients, the quality of life of the nurse is also improved because of the palliative care they provide. The nurses in my study appreciated the "intimate relationships" they formed with patients and their families, as well as being appreciated and being needed. Ablett and Jones (2007) maintain that it is these interpersonal relationships that may enable hospice nurses to remain resilient and effectively buffer or moderate the stressful effects of working in palliative care. I feel that this is borne out in my study not only by the nurses' comments themselves, but in the way they talked about the rewards of personal relationships interspersed with their comments about stress.

One nurse mentioned the work adding to her own understanding of death. Kubler-Ross (1969) recognized the value to oneself of this work when she said, "If we are willing to take an honest look at ourselves, it can help us in our own growth

and maturity. No work is better suited to this than dealing with the very sick, old, or dying patients" (p.61). This theme was not explored fully in my study, but it was evident from comments such as "we all are terminal" that nurses had to some extent come to terms with their own mortality.

Vital Signs

The routine taking of vital signs at end of life was one of the big differences that I noticed in caring for people in the US compared with the UK. The answers to why this is the case were varied. Some of the answers could be seen to be reflective of Berry and Griffies' (2010) comment that "as nurses we derive a good deal of security in performing the ritual of measurement of vital signs, one of the hallmarks of good nursing care" (pp.631,633). This was borne out by the comments, "I always have" [taken vital signs], and "It makes me feel that I have done the right job". Another nurse explained it was part of her head to toe assessment. Indeed it is an expectation of the hospice agency employing these nurses that the vital signs are recorded on the nurse visit form once a week.

Most nurses in the study including the Specialist Palliative Care Nurse talked about the predictive powers of vital signs in the timing of a death. All the nurses I interviewed felt that they could tell just as well that the patient was dying or even how close they were with other signs, such as breathing changes which they deemed to be more reliable indicators. This finding is in line with the answers given in by respondents in Dendaas' (2002) study that also recognized the unpredictability of vital signs in terms of length of expected survival.

Another reason for taking vital signs mentioned by several of the nurses I interviewed was the important part they played in alerting them to a symptom that could be treated. I found nothing in my literature search that cited this as a reason for taking vital signs; most of the literature was focused on the terminal or last days of life. However this could be seen as reassuring that patients were not being "given up on." This idea of being given up on seemed to emerge from the overwhelming reason given by the nurses interviewed for taking vital signs in someone that is dying, mainly that of appeasing the family.

Taking vital signs for the family's benefit seemed to me to be one of the most surprising outcomes of the study, and was mentioned by all of the nurse respondents. The comments by the advanced palliative specialist nurse gave further credence to this argument, when she mentioned her changed opinion and stance on this subject. Although several authors mention that nurses can hide behind these technical functions, the specialist nurse together with one of the home hospice nurses talk of it being "a way in to do other tasks." There was no evidence that the nurses in this study were neglecting other areas of care in favor of taking vital signs. They were committed to the holistic care of their patients, and saw it as a part of giving the very best care possible.

The observation by the specialist nurse that having a blood pressure taken is such an inherent part of health care that to forgo this seems to be too big a step for families seems to tie in with Sandelowski's observations of the relationship of nursing and technology (1999), particularly within the American culture, and could be seen as a way that technology is being used to comfort families.

Some nurses in the study recognized that taking vital signs might not always be appropriate at the end of life. Rather than Johns' (2005) idea that nurses could be distracted, the nurses in this study felt it was distracting the families. One felt that this was a sacred time (and tried to wean her families off an over-reliance on them); another recognized that families put so much store on the results of things like oxygen SATs that it could actually affect the climate of care. I have personally observed these measurements causing anxiety in families as they seek detailed physiological explanations as these numbers rise and fall, sometimes even expecting a recovery when readings were not as bad as expected.

The taking of vital signs at the end of life appears from this study to be a small but integral part of the physical care of a person at the end of life in American hospice nursing as observed in Utah, and although seen as not always necessary as regards changes to care, families do seem to derive security from this. Although Dame Cicely Saunders felt that other things could be more useful, she acknowledged the different amounts of technology in the early palliative care settings, "Some have portable x-ray equipment, some do not even take temperatures" (Saunders, 1960 in Clark, 2006, p.23).

Documentation

All of the nurses in the study recognized the importance of documentation; the overarching reason for completing documentation cited by all of the respondents was legal necessity. The nurses questioned understood the possible legal comeback that might be launched by an unhappy family member. Although other reasons

were mentioned these were usually second to this. This could reflect the litigious nature of American society. Although all nursing notes are regarded as legal documents in the UK, this is normally (in my experience) considered secondary to the purpose of communication. Keeping documentation in the house rather than the agency office in the UK seems to facilitate this communication and could be seen as a further attempt to involve the patient and family in the care. Having forms that require full assessment of all bodily systems may be seen as not as relevant at end of life as the checkbox system of only likely end of life symptoms in the Liverpool Care Pathway used in England.

The overwhelming amount of paperwork and the amount of duplication which the participants ascribed to the billing and eligibility requirements of Medicare and the insurance companies was noted by many of the respondents in my study a source of stress. This was in line with Kulbe's (2001) study. Kulbe suggests that agencies should seek input from their nurses as to how to more efficiently meet necessary documentation requirements, and consider the use of computers to help with this. Interestingly one of the respondents in my study mentioned her frustration with the inefficiency of the current system and suggested computers as a way to improve the situation.

The fact that the nurses in my study felt that a place for narrative was important to document such things as spiritual concerns illustrates the importance they put on holistic, individualized care, and is encouraging. This could be seen to refute the speculation of Gunhardsson et al. (2007) that often psychosocial concerns can be neglected in favor of physical symptoms by palliative care nurses.

Comparisons of Hospice Nursing in the USA and UK and Recommendations

In my opinion hospice nurses in both the UK and the USA could learn from each other's practices. The nurses in Utah displayed more awareness of the pure idea of hospice nursing that Dame Cicely conceived than their British nurse counterparts (community nurses) particularly the acknowledgement of its spiritual dimensions. Working with an interdisciplinary team may make the other dimensions of care more apparent, as well as facilitating delivery of holistic care.

The strength of the American system of hospice care at home seems to me to lie with the interdisciplinary team. Interdisciplinary team work was seen in this study as essential to meeting patient goals, addressing all aspects of patient need, and as a personal support network for the nurses themselves. Dame Cicely envisioned this interdisciplinary approach and although it exists in the UK within hospice buildings, for homecare patients this service seems less accessible. In the USA all patients receiving hospice care in the home are offered the services of at least a chaplain and social worker in addition to medical and nursing care, at the start of service. Assuming that all patients have spiritual and social needs as well as physical needs and making different professionals an integral part of the care rather than calling them in on an ad hoc basis for difficult situations (as is the case in the UK) I feel would be bound to improve care.

A comparison of the MacMillan specialist palliative care nurses in the UK to the Utah hospice nurses may be more favorable; however it is the community nurses who deliver the majority of care to people at the end of life in their own homes in

the UK. Community nurses, although they possess a similar desire to provide quality palliative care and recognize its importance and rewarding nature, face more challenges in delivering this ideal. My personal experiences of working in both systems show that community nurses have considerably less time to focus on the needs of palliative care patients. Not having time to do the job properly or to meet the expectations of themselves and others was cited by several of the Utah hospice nurses as being a source of stress, so under these conditions they too would probably perform less effectively.

The thorough physical examinations, including taking vital signs and oxygen SATs performed by nurses in the USA may be of use in the earlier stages of the terminal illness trajectory, highlighting treatable problems, and could possibly enhance the care given by UK nurses. However in the end stages, focusing on specific end of life symptoms (as in the UK) may be more efficient. The Liverpool Care Pathway may eliminate unnecessary procedures as well as reducing paperwork. Following the UK practice of leaving documentation in the home may reassure patients and their families. I can see no benefit in British nurses adopting the idea of the routine taking of vital signs at the very end of life, as its only merit seems to be to be to reassure families. Based on my experience of working with dying people in England, I have not observed a need for this among family members. Patients in the UK like their American counterparts would have been used to having vital signs taken at each medical encounter, but possibly the difference lies in the nature of the healthcare system in the USA in which patients have more say in the commissioning of their services as opposed to the British system which is

seen as more paternalistic (Remington & Wakim, 2010). With the emphasis on self management being encouraged in the UK, this may become an issue in the future.

One of the merits I see of the structure of the British system would be the easier access to palliative care patients being cared for by nurses at home at an earlier stage in a chronic illness trajectory, which may for some be many years before their death. Although broadening eligibility criteria may add to workload stress.

Strengths and Limitations of the Study

Although I found one study comparing structure of hospice care in the US and UK, none to my knowledge have compared practice. As well as gaining personally in my understanding of hospice care as practiced in the USA, I am optimistic that the nurses that took part in the study also gained from reflecting on questions asked by a foreign nurse that they may not have asked themselves. I feel there is much to be gained by questioning nursing practices which otherwise can become automatic and ritualistic.

A major limitation of this study is that although many common themes were repeated, data collection did not reach saturation, due to the time constraints of a master's thesis. This was also a small study. Although the study participants varied in age, experience and gender, all were White American. As far as transferability is concerned it is recognized that the selection of participants was from one hospice in Utah, as such it may only be representative of just that. Coding and interpretation of the transcripts was performed alone due to time constraints. Credibility would have

been enhanced by involving another person in this process. My comparisons of hospice care in the UK and the US have been based on working in the same agency as my respondent nurses in Utah, USA, and two areas in the South West and South East of England.

Further plans include returning to the participants in a focus group setting, which all participants consented to do, with the expectation that this would improve the richness and credibility of the data. Repeating the study with British Community Nurses as the respondents might allow for a more accurate comparison.

Ideas generated by this study as possible further areas of research would be to look at the involvement of families in the care of hospice patients, and the extent to which their decision making may affect patient care, also whether the decisions family members make accurately reflect patient wishes. The family's role in pain relief and medication management would also be an interesting subject for further investigation. Pain relief at end of life is usually delivered by continuous subcutaneous route in the UK, and is thus controlled by the nurses, rather than reliance on family members for medication administration. Examining the particular stresses experienced by on call nurses might also prove interesting.

CONCLUSION

As a nurse with a keen interest in end of life care I have learned much from carrying out this study. My own perspective of hospice care and how it can be delivered has been broadened by talking to nurses from another culture and reflecting on the differences. Dame Cicely Saunders and the early pioneers of hospice care in America envisioned the philosophy of hospice being adapted to different settings. It has been an interesting experience to observe this in action.

My hypothesis that cultural norms may override hospice philosophy was not fully substantiated. The variance in practice that I had noticed from the UK, such as the taking of vital signs, could be attributed to family expectation, fostered by the routine medical care or the acute care patients and families had previously experienced. It could be seen as medicalization of the dying pervading even the hospice setting, or simply the way hospice care has adapted to fit the American culture. Measuring vital signs even when not medically indicated could be seen as a part of caring for the family which is an inherent part of hospice philosophy.

Dame Cicely Saunders' mandate, "We will do all we can to help you, not only to die peacefully, but to live until you die" seems to be borne out in the attitudes of the hospice nurses whom I interviewed in Utah. Their ideas of the philosophy of hospice also closely match the holistic care she espoused, with emphasis not only on the physical aspects of care but the emotional, psychological

and spiritual domains also. The care they provided was also centered toward meeting the needs and goals of their patients, recognizing their individuality, and respecting their personhood.

In line with other research, stresses of the job seemed to stem more from workload demands rather than the nature of the work. All of the nurses recognized the potential toll of repeated loss and grief, and had developed coping mechanisms. That the challenges posed by the job were offset by the rewards was recognized by most of the nurses. All of those with longer nursing careers felt this was the most rewarding nursing they had ever done.

APPENDIX A.

INTERVIEW GUIDE

Research Question 1

- What is the participant's idea of hospice philosophy?
- What distinguishes hospice care from homecare nursing?
- What does the participant perceive the aims of hospice nursing to be?
- What would the participants view as priorities of care?

Research Question 2

- How does the participant see this philosophy articulated in their provision of care?
- In their assessment and observation of patients, how relevant are vital signs?
- Under what circumstances might the participant deviate from the expected provision of care?
- What is the purpose and relevance of documentation?
- What are the benefits of working within the interdisciplinary team?

Research Question 3

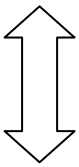
- What other factors does the participant feel might influence hospice care delivery, generally or personally?

APPENDIX B

THE INTERPRETIVE PROCESS

Stage 1: Interpretation of individual data

The Interpretive Process



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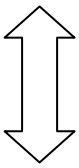
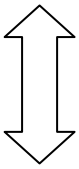
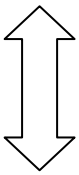


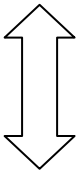
Significant statements extracted



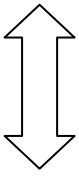
Grouped under predetermined themes



Loose emerging themes developed



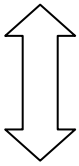
Extended themes developed



Validation with group

Stage 2: Interpretation of collective data, emergence of key themes

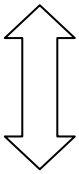
Merging of first level themes. Emergence of key themes.



Formulation of major aspects of hospice philosophy and hospice nursing

Stage 3: Interpretation of integrated data, emergence of the "story" of hospice nursing in Utah.

Interpretation of data within each major aspect of philosophy and practice.



Emergence of the interpretive story and the meaning of hospice nursing to these nurses

Evans, M.J. & Hallett, C.E. (2007). Living with dying: a hermeneutic phenomenological study of the work of hospice nurses. *Cancer and Palliative Care 16,* 742-751

REFERENCES

Abendroth, M., & Flannery, J. (2006). Predicting the risk of compassion fatigue, A study of hospice nurses. *Journal of Hospice and Palliative Nursing, 8* (6), 346-356.

Ablett, J. R., & Jones, R. S. P. (2007). Resilience and well-being in palliative care staff: A qualitative study of hospice nurses' experience of work. *Psycho-oncology, 16,* 733-740.

Anger over Hospice Funding Lottery. (2011). E.A.D.T. News http://www.eadt.co.uk/news/anger_over_hospice_funding_lottery_1_75770

Benner, P. (1984). *From novice to expert.* Menlo Park, CA: Addison- Wesley.

Beresford, L. (1993). *The hospice handbook.* Boston, MA: Little, Brown and Company.

Berry, P., & Griffie, J. (2010). Planning for the actual death. In B.R. Ferrell & N. Coyle (Eds.) *Oxford textbook of palliative care*. New York: Oxford University Press.

Brownlea, S. (2007). *Over treated.* New York, NY: Bloomsbury.

Buck, J. (2007). Reweaving a tapestry of care: Religion, nursing, and the meaning of hospice, 1945-1978. In P. D'Antonio, B. Mann Wall, & E. Weiss (Eds.). *Nursing history review.* (pp.113-145). New York: Springer Publishing.

Byock, I. (1997). *Dying well.* New York, NY: Riverhead Books.

Cassell, E. J. (1991). *The nature of suffering and the goals of medicine*. New York, NY: Oxford University Press.

Chochinov, H. M., Hack, T., Hassard, T., Kristjanson, L. J., McClement, S., & Harlos, M. (2005). Dignity therapy: A novel psychotherapeutic intervention for patients near the end of life. *Journal of Clinical Oncology, 23* (24), 5520-5525.

Clarke, D., (2006). *Cicely Saunders selected writings 1958-2004*. Oxford, UK: Oxford University Press.

Coventry, P. A, Grande G. E., Richards, D. A., & Todd, C.J. (2005). Prediction of appropriate timing of palliative care for older adults with non-malignant life

threatening disease; a systematic review. *Age and Ageing 2005*, (*34*) 218-227 doi:10.1093/ageing/afi054

Dendaas, N. R. (2002). Prognostication in advanced cancer: Nurses' perceptions of the dying process. *Oncology Nursing Forum 29* (3) 493-499.

Doyle, D. (1998). The provision of palliative care. In D. Doyle, W.C. Hanks, & N. Macdonald (Eds.). *Oxford textbook of palliative medicine* (pp.41-51). New York, NY: Oxford University Press.

Elisabeth Kubler- Ross Foundation., (2011). *Eulogy. Authors.* http://www.ekrfoundation.org/eulogy

Ellershaw, J. (2003). Care of the dying patient: The last hours or days of life. *BMJ 326,* 7379-30 http://www.bmj.com/content/326/7379/30.full

Evans, M. J., & Hallett, C.E. (2007). Living with dying: A hermeneutic phenomenological study of the work of hospice nurses. *Cancer and Palliative Care 16*, 742-751

Evans, N., & Walsh, H. (2002). The organization of death and dying in today's society. *Nursing Standard 16* (25), 33-38.

Furst, C. J., & Doyle, D. (2005). The terminal phase. In D. Doyle (Ed.) *Oxford textbook of palliative medicine,* New York, NY: Oxford University Press

Ferrell, B. R., & Coyle, N. (2008). *The nature of suffering and the goals of nursing*. New York, NY: Oxford University Press.

Gaydos, H.L.B. (2004). The living end, life journeys of hospice nurses. *Journal of Hospice and Palliative Nursing*. *6* (1), 17-26.

Gunhardsson, I., Svensson A., & Bertero, C. (2007). Documentation in palliative care: Nursing documentation in a palliative care unit- A pilot study. *American Journal of Hospice and Palliative Medicine. 25* (1), 45-51. doi:10.1177/1049909107307381

Henetz, P. (2011). Study: Utah again tops on end-of-life care measures. *The Salt Lake Tribune.* Apr 11, 2011. Retrieved from http://www.sltrib/news/51608042-78/care-hospice-patients-hospitals.html.csp 4/14/2011

Heidegger, M. (1962). *Being and time.* New York: State University of New York Press.

Hospiscare (2010). *Annual review.* Exeter, UK: Author.

Hutchings, D. (2002). Parallels in practice; palliative nursing practice and Parses' theory of human becoming. *American Journal of Hospice and Palliative Care. 19* (6), 408-414.

Johns, C. (2004). *Being mindful, easing suffering.* Gateshead, UK: Athenaeum Press.

Johns, C. (2005). Reflection on the relationship between technology and caring. *Nursing in Critical Care 10* (3), 150-155.

Johnson, D.C., Kassner, C.T., Houser, J. & Kutner, J.S. (2005). Barriers to effective symptom management in hospice. *Journal of Pain and Symptom Management. 29* (1), 69-79.

Johnston, B., & Smith, L. R. (2006). Nurses' and patients' perceptions of expert palliative nursing care. *Issues and Innovations in Nursing Practice. 2006,* 700-709.

Jones, A. (2003). On projective identification, containment, and feeling special: Some thoughts about hospice nurses' experiences. *American Journal of Hospice and Palliative Care. 20* (6), 441-446. doi: 10.1177/104099091030200060 6

Kehoe, M. H. (2006). Embodiment of hospice nurses, A metasynthesis of qualitative studies. *Journal of Hospice and Palliative Nursing 8* (5), 137-146.

Kehl, K. A. (2008). Caring for the patient and family in the last hours of life. *Home Health Care Management Practice 20* (5), 408-413. doi: 10.1177/1084822303311839

Kubler Ross, E. (1969). *On death and dying.* New York, NY; Scribner.

Kuhl, D. (2002). *What dying people want.* New York, NY: Public Affairs.

Kulbe, J. (2001). Stressors and coping of hospice nurses. *Home Healthcare Nurse. 19* (11), 707-711.

Lentz, J. (2004). A conversation with Florence Wald. *Journal of Hospice and Palliative Nursing 6* (1), January-March 2004

Madajar, I. (1998). *Giving comfort and inflicting pain* Alberta: Qual Institute Press.

Maltoni, M., Caraceni, A, Brunelli, C., Broekaert, B., Christakis, N., Eychmueller S., & Kaasa, S. (2005). Prognostic factors in advanced cancer patients: evidence based clinical recommendations- A study by the steering committee of the European Association of Palliative Care. *Journal of Clinical Oncology 23* (25), 6240-6248.

Marrelli, T. M. (1999). *Hospice and palliative care handbook. Quality, compliance and reimbursement.* St Louis, MO: Mosby.

Martens, M.L. (2009). A comparison of stress factors in home and inpatient hospice nurses. *Journal of Hospice and Palliative Nursing. 11* (3). 144-153.

Mc Connell-Henry, T., Chapman, Y., & Francis, K. (2009) Husserl and Heidegger: Exploring the disparity. *International Journal of Nursing Practice 15* 7-15. doi: 10.1111/j.1440-172X.2008.01724.x

Mercer, J., & Feeney, J. (2009). Representing death in psychology: Hospice nurses' lived experiences. *Mortality 14* (3), 245-264.

Meystre, C. J. N., & Burley, N. M. J. (1997). What investigations and procedures do patients in hospices want? Interview based survey of patients and their nurses. *BMJ 314* (7117) *Care Management Practice 20* (5) 408-413. doi: 10.1177/1084822303311839

National Hospice and Palliative Care Organization (2011). *What is Hospice and Palliative Care?* Authors. Retrieved from http://www.nhpco.org/i4a/pages/index.cfm?pageid=4648

Olthius, G., Leget, C., & Dekkers, W. (2007). Why hospice nurses need high self esteem. *Nursing Ethics. 14* (1), 62-71.

Padgett, D.K. (1998). *Qualitative methods in social work research.* Thousand Oaks, CA: Sage Publications.

Paice, J.A. (2007). The Interdisciplinary Team. In L.Emmanuel and P.Librach (Eds.), pp.475-485. *Palliative Care: Core Skills and Clinical Competencies* Philadelphia, PA: Saunders Elsevier. pp 475-485

Payne, N. (2001). Occupational stressors and coping as determinants of burnout in female Hospice nurses. *Journal of Advanced Nursing*. *33*, (3) 396-405.

Polit, D., Beck C. & Hungler B. (2001). *Essentials of Nursing Research* Philadelphia, PA: Lippincott.

Remington, R., & Wakim, G. (2010) A comparison of Hospice in the United States and the United Kingdom, Implications for Policy and Practice. *Journal of Gerontological Nursing 36*, (9) 2010.

Rocky Mountain Care. (2006). *Signs and symptoms of approaching death*. Salt Lake City, Utah: Author.

Sandelowski, M. (1999). Troubling distinctions; a semiotics of the nursing/technology relationship. *Nursing Inquiry. 6,* 198-207.

Saunders, C. (1961). And from sudden death. In D. Clarke (Ed.) (2006). C*icely Saunders selected writings 1958-2004*.(pp. 223-228) Oxford, UK: Oxford University Press. Reprinted from Frontier (Winter 2001).

Saunders, C. (1989). Hospice-a meeting place for religion and science. In D. Clarke (2006) *Cicely Saunders selected writings 1958-2004* (pp. 223-228) Oxford, UK: Oxford University Press. Reprinted from *Science and Faith*, pp. 263-276, by T. Vanier, Paris, France: Flammarion.

Saunders, C. (1998). Foreword in D. Doyle, G.C.W. Hanks & N. MacDonald (Eds.) (1998). *The Oxford textbook of palliative medicine* (pp vi-ix) New York, NY: Oxford University Press.

Skilbeck, J., Corner, J., Bath, P., Beech, N., Clark, D., Hughes, P., & Webb, T. (2002). Clinical nurse specialists in palliative care. Part 1. A description of the Macmillan Nurse caseload. *Palliative Medicine 16,* 285-296.

The Dartmouth Atlas of Health Care, (2010). *Understanding the efficiency of the Health Care System.* Retrieved from http://www.dartmouthatlas.org/ 11/17/2010

The Marie Curie Palliative Care Institute (2010). *What is the LCP?* Liverpool, UK: Marie Curie Palliative Care Institute, Liverpool.

Watson, M., Lucas, C., Hoy, A., & Wells, J. (2009). *Oxford handbook of palliative care.* Oxford, UK: Oxford University Press.

World Heath Organization (2002). *National Cancer Control Programs.* Geneva, Switzerland: World Health Organization.

Wright, D. (2001). Hospice nursing: The specialty. C*ancer nursing 24,* (1) pp.20-27. Retrieved from http://ovidsp.tx.ovid.com/sp-33.0b/ovidweb.cgi?QS2=434f4e1a73d37e1a73d37e8c9ea8b035782f3c4